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**A nomadic exploration of quality of life in  
long-term conditions**

M.M.P. Lhussier

PhD

2006



# **A nomadic exploration of quality of life in long-term conditions**

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A thesis submitted in partial fulfilment of the  
requirements for the degree of Doctor of  
Philosophy of Northumbria University

School of Community, Health and Education  
Studies

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## **Abstract**

The nature of quality of life and its consensual definition has eluded researchers and philosophers ever since Aristotle. While social indicators researchers seek to model it in order to inform policy, it is used as an outcome measure of health care. Although studied from a variety of perspectives, the concept has, as yet, been largely untouched by postmodernists. In this thesis, quality of life is studied through the frame of long-term conditions. Within this, I use the Deleuzo-Guattarian concepts of the body without organs, its territorialisation by societal forces and the emancipatory promise of nomadism. Three health service developments for people with multiple sclerosis, a sample of television programming, a Disney Classic feature and the National Service Framework for long-term conditions form the case material for the study.

I take the reader through a deterritorialising textual journey, so that quality of life may be approached differently. Qualitative research chapters are alternated with those analysing the political and cultural background to their making. These texts are woven into a deconstruction of quality of life in the five oppositional pairs of life and death, health and illness, independence and dependence, empowerment and disempowerment and certainty and uncertainty. This deconstructive thread informs and is informed by the texts studied, in a (rhizomatic) dis-order used to blur boundaries between established categories.

A temporary reterritorialisation of quality of life emerges, which highlights the construction of the self as an endless process. Powerful discourses, such as medicine, shape a quality of life text for people with long-term conditions. Deterritorialisation, as a process, enables the acknowledgement of such territorialising forces and encourages a different engagement with life. The body as a dys-organ-ised entity with erratically evolving possibilities becomes a territory, and quality of life the potential to engage in a liberating process of deterritorialisation.

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## **Author's declaration**

This work has not been submitted for any other award of this or any other university. Although some of the data presented were collected for other purposes, I alone have collected and analysed all the data included in this thesis.

Monique Lhussier,

November 2006.

# INTRODUCTION

Reflections on quality of life have a long tradition in philosophy and have been the focus of considerable academic endeavour for the best part of 50 years. Despite this, over one hundred different definitions of quality of life were identified in the literature over ten years ago (Cummins 1995). Philosophically, accounts of the ‘good life’ can be traced back to Aristotle’s (384-322 BCE) work. Philosophers have drawn on perfectionism, hedonism, preference theory, or have adopted a hermeneutic approach to the concept. Academically, quality of life has predominantly been studied from either positivist or phenomenological perspectives, but has as yet been largely untouched by postmodernists. So the notion of quality of life is not new and has given rise to a plethora of philosophical, ethical and academic debates. These all draw on fundamentally different approaches and have yet to produce a universal understanding about what quality of life may be. The phrase ‘quality of life’ itself is ambiguous. It can refer to a characteristic of the life in question, or it can be the felt quality of the experience of life. While the first understanding is the basis of the perfectionist thought and of the early eugenic movement, subjectivists use it in the second sense. Social indicators researchers generally consider the quality of life as an umbrella term that should cover both conditions of living and subjective well-being or happiness (Veenhoven 2000). This movement has given rise, for example, to the first edition of the *Journal of Happiness Studies* in 2000. However, as the health care literature most commonly uses the term ‘quality of life’ (Bowling 2005), it will be the preferred term in this thesis. So in itself, the use of ‘quality of life’ does not suppose allegiance to any theoretical perspective or academic discipline. A postmodern stance, such as that used in this work, not only acknowledges this, but also highlights the fact that the phrase does not have an essence in itself, but is rather used in different discourses to different effects.

Quality of life is studied in medicine, psychology, economics, environmental or legal studies, ethics and many other fields. Quality of life researchers from all those

disciplines and more, through the creation of the International Society of Quality of Life Studies for example, are currently striving to gain recognition as a unified academic discipline (see for example Hagerty et al. 2001; Sirgy et al. 2006). While the conceptual boundaries of quality of life have yet to be firmly established, it is being 'disciplined' in order to occupy a 'legitimate' academic space. It may be for this reason that the contemporary focus of quality of life research remains largely embedded in a positivist and scientific paradigm, in producing quality of life measurement scales and country-wide population studies (Veenhoven 1996; Hagerty et al. 2001; Michalos 2004).

This work does not have the pretension to compete with, or corroborate, any of the approaches or systems of belief that have differed on quality of life for centuries. Neither will it contribute to the 'disciplining' of the concept. Rather, it is about how quality of life is referred to in contemporary discourses. It is about quality of life representations and it aims to disrupt prior understandings of quality of life by providing a space - this thesis - where critical thinking can happen and where assumptions can be questioned. This work takes long-term conditions as a frame within which quality of life is studied. Such a frame puts inevitable limits on the knowledge developed, but like Cilliers (2005), I consider them not as a negative, but as a necessary condition to knowledge generation. My approach is therefore inherently cross-disciplinary and situates itself at the intersection between health and quality of life studies. It takes, for objects of study, research, policy and media texts.

Its objectives are to explore how quality of life in long-term conditions is conceptualised as a frame within a frame, manifesting itself through a diversity of discourses, territories or texts. I use a postmodern deconstructive approach in order to surface the assumptions that underpin our understanding of the concept. This work also breaks new ground in considering the quality of life of people with long-term conditions as a text that both participates in making and is also inevitably influenced by wider cultural trends.

In this study, quality of life is seen as a concept or a text, which itself interpenetrates other texts. I seek to identify the current explanatory systems that frame quality of



life in the context of the National Health Service, in the views of people with long-term conditions and in the wider culture in which they live. I use three textual sources to this effect:

- (1) The evaluation of three physiotherapy service developments for people with Multiple Sclerosis (MS). This includes interviews with service users and providers, field notes and the use of one quality of life measure, the Schedule for the Evaluation of Individual Quality of Life (SEIQoL, O'Boyle et al. 1993);
- (2) A content analysis of popular television programmes and a deconstructive analysis of a Classic Disney feature; and
- (3) A deconstructive analysis of the National Service Framework for Long Term Conditions (DoH 2005).

The use of such diverse data strands, each representing a different text within the frame of long-term conditions, has the purpose of presenting how quality of life is being referred to in different contexts. This work aims to provide a space for the reader to *stand back* from the current widely accepted assumptions underlying our understanding of the quality of life of people with long-term conditions. It aspires to enable a questioning of those assumptions and a widening of current understandings of it. Ultimately, it seeks to promote the recognition and valuing of difference between individuals in the life they lead. The structure of the thesis is the result of three interwoven journeys, which are described in the following pages: a personal, a philosophical, and a textual journey.

### **A personal journey**

Looking back, my inclination to nomadism started when I was about three years of age, and wanted to go to 'school' on my own. These were my first attempts to approach the world differently and for the rest of my school years I walked to school everyday, on my own. At college, I had discovered in myself a passion for biology and, at eighteen, applied to every university in France offering what I wanted: a two-year course in applied biology. Human biology fascinated me and I was forever in the library, learning more than I needed for the course. The biomechanics of human life were for me a source of constant wonder. On graduation I finished first in my

year. This had been a short university course that trained people to be immediately employable.

Then twenty, the responsibilities of a working life scared me. I knew I could study and I was suited to the bohemian lifestyle of a student. So I applied to the engineering school across the road from my university. Three years later, I was an engineer in applied biology, deemed capable to work in any industry using biological processes, from recycling water to the food, pharmaceutical and cosmetics industries. I also had a Masters in nutrition, which I had done concurrently with my last year. I went back to live at my parents' home and looked for a job from there.

To this day, I am not quite sure what drew me to an advert that sought people 'prepared to work with refugee populations'. I did not even know what refugees were, or where they could possibly live. I had an interview in Paris; they were looking for volunteers to go to Sierra Leone. It was November 1995 and I was to leave in March the following year. Full of apprehension, after a brief week of training in Paris, I took the plane for Freetown, Sierra Leone. I was to be posted in Bo, a small town in the south of the country, where I was in charge of the running of food distribution points for moderately malnourished children. I was 23 and managing nearly 50 local staff who ran home visiting and health education programmes. It was a steep learning curve and of course, *so* irresponsible on the part of the agency. But all went well and after nine months, I was transferred to north Uganda to run similar programmes. I came back home in March 1997.

The organisation got back in touch a couple of months later and gave me the choice between going to Burundi or Afghanistan. I left for Kabul in May 1997, where I was to be posted for the following 15 months. I had been given the pompous title of 'medico-nutritional co-ordinator', which entitled me to manage five expatriates, themselves in charge of various nutritional and educational programmes. These were probably the most important months in my life so far, in that they have had a significant and lasting impact on the person I have become. Afghanistan is a magnificent country inhabited by mysterious, fascinating, fiercely independent and proud people. Some of the most striking people we served were nomads. I have

probably romanticised all of my memories of it, but so have all the people I know who have ever been there. I left Afghanistan after a second emergency evacuation in August 1998.

The 'traumatism' of coming back home is a well-recognised phenomenon amongst people who have travelled to developing countries. People come back to a place that they had, up to now, considered as home and yet feel deeply at odds with. The rampant consumerism becomes intolerable. People's negative moods, incessant complaints and depressions feel unacceptable. I was no exception to this, and like every other volunteer coming back, it took me a long time to stop comparing the incomparable. I felt I couldn't connect with my own people any more. They did not understand how much they had it all, and how much the world was suffering. I had seen children dying of hunger. I had seen the results of torture. I had encountered a case of cannibalism. But I had also met the happiest, cheeriest people. These populations, which we in the West would classify at best as vulnerable, experienced happiness. Often, people's sense of values and the value they put on life itself, were alien to me and I was resigned to the fact that I would probably never be able to understand them. But I had also lost touch with the culture in which I grew up, where people, lost in their worldly possessions and inflated sense of self, had lost any common sense about what was *really* important. The futile had become their prime concern. All these feelings infuriated me and scared me; deep down, I knew I was the one who had changed. It was time to settle down or I would become one of those forever travellers who belong nowhere and anywhere at once. I was not ready for true nomadism.

Since I saw employment as a first step to my re-integration, I came back home to look for a job once more. I got my first interview eight months later in Newcastle, and moved 'up here' in June 1999. Seven years later and I am still here, now a professional woman, a wife and a mother. All these roles that I had spent so much effort avoiding and here I am, like a lot women of my age: 'settled'. I have had time to step back and reflect upon my experiences. Even though I now see the nonsense and the pointlessness of some of the things I have done, I do not regret any of them. All together and with other influences and experiences, they have contributed to the

making of the person I am today. I still wish I could make the world a better place to live in, but experience has told me that without a strong political will supporting this, it is an impossible task. So it is no wonder that I was drawn to study the quality of life of people who we, healthy people, would often qualify as vulnerable in a favourable UK political climate that vows to put “people at the heart of public service” (DoH, 2004). Like people in developing countries, people with long-term conditions are often seen as deprived. They are both lacking something, which is often seen as the condition *sine qua non* for a good quality of life. In one case it is wealth, in the other health. Yet in both sets of people I have seen happiness. As developed countries impose their democratic and capitalist views on poorer countries, does the healthy elite conceptualise quality of life in a framework that necessarily puts ‘unhealthy’ people at the periphery and denies them the right to a good quality of life?

Writing these pages is not just egocentric indulgence, but aims to give the reader a glimpse of who I am and what I bring to this research. Every researcher brings a unique set of values and experiences to the research context and it is an important step to recognise and expose those, but I will come back to this a little later.

### **A philosophical journey**

Conceptually then, I came to the UK with positivist baggage gained over my student years. I then moved from a fascination for life in its bio-mechanistic workings, to a resolve to explore the possibilities of a more humanistic stance. My position at Northumbria University enabled me to interview people with learning disabilities and their families, people who had had a stroke and people with end-stage renal disease. Interviewing people with what I perceived as ‘real’ problems in many ways brought back to life my existential concerns. It is with people with end-stage renal failure that I measured quality of life for the first time. The measurement tool we used, the SEIQoL (O’Boyle et al. 1993), consisted of asking people their five most important life areas. Interestingly, although the participants’ life seemed to be greatly shaped by their disease state, very few nominated ‘health’ as an important life

area (Lhussier et al. 2005). This puzzled me: if health was not important to people who spend a considerable amount of time in contact with the health care system, what was? What were the determinants of these people's quality of life, and to what degree did their health status influence it? My quest for the meaning of quality of life had started and, at that point, my research question became: Could and should individual quality of life become an outcome measure of health services in their attempt to adapt to the needs of people with long-term conditions?

When I came to think about which theoretical framework to adopt for this thesis, my first instinct was to use critical theory. Along with recent NHS policy documentation (DoH 2001b; DoH 2002), I saw patients as disempowered in an over-controlling health care system. I thought quality of life research had the potential to give people a voice and to highlight the possibility of health as not being central to their life at all times. This project was going to provide a better understanding of the quality of these people's lives and enable the publication of their concerns as disempowered service users. It was going to be congruent with social critical theory in providing a voice to lay experiences and using it to challenge the biomedical model of health care. I was seeking to confront and reduce injustices in our health care system through the knowledge produced by my research.

In the meantime, I was approached to be part of a national evaluation of newly developed services for people with Multiple Sclerosis (MS). This appeared to be the ideal opportunity to test my assumptions. I was going to be able to interview service users and providers and to assess their perceptions of life with MS. The health professionals, in putting all their time and energy into using the health care system to provide better services for their patients, were the first to shake my initial appeal for critical theory. They were seeking to improve the well-being of their service users and, most of the time, the system facilitated their efforts. At the same time, few of the patients I was speaking to seemed to feel oppressed, or willing to be emancipated. Most were in control of the amount of input they wanted from health services and wanted to be seen as malfunctioning biomechanical bodies in that context. They often did not want a patronising and intrusive type of care, but one that was solely going to improve the functioning of their body. Provided that this

was under control, they were quite capable of dealing with the rest of their lives. They were not passive agents of an overpowering medical domination and did not necessarily require to be liberated from an oppressed patient position. As a result of these encounters, the initial appeal of critical theory was starting to fade. How could I possibly know how oppressed, or not, people really were? And would they be willing to be emancipated anyway? This is congruent with the main criticism of critical theory (Agger 1998). Even if they were, I was not convinced that my research results would be capable of fulfilling such emancipatory goals. I needed to find an alternative to critical theory.

The recent Hollywood production *The Notebook* (2004) had a significant impact on this work. It is a love story told retrospectively, by a man reading over and over again the story of their life to his wife, who has dementia. Occasionally, through the telling of the story, she would recall the events and recognise the man beside her as her husband. These would be the rare but intensely emotional moments for which he would live. In the end, he has a heart attack and is being kept under observation in a medical ward. He escapes the vigilance of a nurse to go and see his wife one last time. She immediately recognises him and they die together. There were elements in the story of medical oppression, but also of agency. The husband was reading the notebook of their life story against medical advice. In the end, love wins and they are reunited, albeit through death. As with the study participants, I could not see critical theory as bringing the right theoretical framework to understand the film. The husband, in acting against medical advice and then escaping medical surveillance to go and see his wife, was clearly in control of his actions. There was an attempt from the medical system to control the main characters' treatment, but quite clearly from their point of view, this was only a marginal issue. What I realised then, is that by looking at the story from a critical perspective, I was standing *outside* of it and thinking about it. It would be the same for my research if I was to use critical theory: I would analyse interview data *from the outside* and produce some sort of thesis *about* the people who spoke to me.

Postmodernism rejects the duality of thought of the Age of Reason, which opposes, for example, mind to body, fact to fiction or insider to outsider's viewpoints (Collins

and Mayblin 1996). A postmodern theorist would look at the possibility of the existence of *The Notebook*. He or she would concentrate on the texts used within it, for example that of eternal love, the medical, legal, biographical discourse or the discourse of loss. All these texts form an illustration of how life with dementia is portrayed in a Hollywood production. They do not exist solely in the film, however, and are in part a reflection of the 'real' world. The Hollywood production then becomes a reflection of how life with dementia is perceived within certain contexts. The postmodern theorist would not only look at this interaction or the commonalities, but also the distinctiveness between the film and reality. He or she would look at *intertextuality* (Appignanesi et al. 2003), or the interactions between the different texts. These conditions of existence of the story lie neither outside nor inside it, but at its limits. Likewise the actors or the production team are neither completely part of the story, nor strangers to it. And, if I adopt a postmodern perspective neither am I, the viewer. What I retain from the film is neither completely linked to the film itself, nor to me as an individual, but to the interaction that happened when I watched it. To me, loss is the overwhelming feeling conveyed by the film. It is the loss of memory for her, loss of a wife and of a conventional married life for him. Death is portrayed as the one place where they can be reunited as man and wife. In this context, death is a return to a social norm of married life, since once dead they can be together for eternity. They could not get a life of the quality they wanted, so they somehow chose to move beyond it. This is how I, with my history, my prejudices and beliefs, perceived this film. It may be that the director did not intend to convey this message and undoubtedly, a different message would have been retained from every other viewer. The producer did not have an idea free from the interference of other ideas or texts. The film, as a text, is not only the conveyor of the producer's ideas, but also speaks for itself. Equally, the viewer can only understand it in relation to a variety of texts and contexts. This concept was introduced by Roland Barthes and is referred to as the 'death of the author' (Barthes 1977). In a postmodern framework, this concept applies to this thesis too, but I will get back to this a little later.

I could begin to see the possibilities of postmodernism as a theoretical framework to approach this work. Postmodernists devalue absolute standards, totalising categories

and overarching accounts, which are seen as oppressive or exhausted. They favour local and contextualised analyses and are cautious of research results presented as absolute truths by authors (Fox 1999). Adopting a postmodern outlook, I cannot present myself as the most competent person to analyse a situation or to produce a prescriptive plan of action. I merely convey an idea through the imperfect means of language. I therefore lack trust in current or produced expert systems and I recognise the existence of multiple truths (Collins and Mayblin 1996).

Adopting a postmodern perspective, I reject the dichotomy between insider and outsider perspectives. Likewise, I reject the mostly binary thinking of our modernist health care system, in which it is common practice to oppose health to illness, mind to body, or objective to subjective outcome measures (Collins and Mayblin 1996). Therefore, I do not see the people included in this study as suffering from malfunctions of biophysical mechanisms in an oppressive biomedical model of healthcare. I see them as people who carry unique experiences of meaning-making in a particular cultural context and who may or may not see themselves as engaged in emancipatory practices.

I am French and was brought up in French society where some of the most prominent postmodern thinkers are celebrated and postmodernism was a hidden philosophical background to my formative years. Since starting this project, reading Foucault, Derrida and Deleuze and Guattari has felt both daunting and strangely familiar. Such is the theoretical journey I have undertaken since my university years. I have gone from a purely positivist stance, from which I admired the mechanics of biological processes, to a complete rejection of its all-encompassing truth, firstly through critical theory and now postmodernism. While travelling, I felt I was like a nomad, passing different environments without ever exerting any control over them. Since discovering postmodernism, I have learnt that one does not need to be physically moving to approach the world in a nomadic way and that nomadic research is a real possibility (Fox 1999). The nomad, as conceptualised by Deleuze and Guattari (1980), celebrates difference through a rejection of any possible grading between elements of the environment. She rejects the organisational power that lies in the naming and ordering of things and views them as inherently spatially and temporally



contingent. She learns as she experiences different texts, but always in the recognition of the temporal nature of this knowledge (Fox 1999). With this in mind, I aim to produce a piece of nomadic research that will be constitutive of difference rather than identity. As such, methodologically, this project attempts to provide an operationalisation of nomadism.

The aim of this project has therefore shifted from an effort to uncover and formulate ontological truths, to an exploration of possibilities of a nomadic stance as conceptualised by Deleuze and Guattari (1980). The concept of quality of life in health care inevitably rests on assumptions, based on our mostly dichotomous system of thought. My intention is to uncover some of these in a bid to disrupt existing understandings of quality of life, through the adoption of a deconstructive, nomadic stance.

### **When did texts become data strands?**

The conceptual journey into this thesis started when I first measured quality of life and explored its relationship to health and functional status (Lhussier et al. 2005). Practically however, it took shape when I became involved in an evaluation of newly developed physiotherapy services for people with MS (Dawson et al. 2004). This involved the qualitative interviewing of service users and providers, and included the SEIQoL (O'Boyle et al. 1993). Three distinct services were to be evaluated, which had a different setting, target group and mode of intervention. Interviews of service users and providers are used in this thesis to explore quality of life conceptualisations, in the context of particular service developments. This study was at the time going to form the primary data strand for this thesis. As I adopted a postmodern outlook, each service development became a text that was likely to assume particular quality of life conceptualisations.

On the basis of the work I had undertaken so far, I was questioning assumptions about the relationship of functional status to quality of life (Lhussier et al. 2005). I sought to value three local and contextual stories of service developments, giving

voice to a range of stakeholders to uncover the multiple conceptualisations of people's quality of life. However, as I philosophically shifted my emphasis from critical theory to postmodernism, I realised the need to acknowledge the macropolitical and cultural landscape in which quality of life assumptions have formed and exist. The qualitative research data included so far were only texts that were influenced by, and that themselves influenced, other texts in an intertextual relationship (Appignanesi et al. 2003). These reflections greatly changed and shaped the format of this work, as I now needed to take my focus away from qualitative research data, to include political and cultural artefacts. I needed to shift mindset and somehow illustrate the dialectical relationship of traditional research data to the world in which they are produced.

The National Service Framework for Long-Term Conditions (DoH 2005) details clinical guidelines and specifies the conditions of care delivery for people with long-term conditions (Checkland 2004). It represents the political background to the three service developments, as well as being itself a text with inevitable intertextual links to quality of life. This was the rationale for its inclusion.

Choosing cultural artefacts proved more challenging. After a short conceptual voyage in the world of media studies, I settled for a Disney Classic production because, as such, it has penetrated our popular unconsciousness (Byrne and McQuillan 1999) and therefore has much to tell us about how we think about quality of life. *Pinocchio* (1940) is a text telling the story of a wooden puppet who wants to become real. His wooden condition is long-term in that we do not know if one day he will become a real boy and his goal to become flesh and blood has curative undertones. Gripsrud (2002) contends that television plays a role in the construction of our identities. If this is the case, then it inherently influences how we come to think about our life and its quality in various circumstances. I therefore decided to include a sample of current television programming as a second media text.

My aim was to see quality of life in long-term conditions as a text, to which I could gain access through other texts. I was going to analyse these intertextual links and how they contributed to forming quality of life's underlying constructs.

## Structure of the thesis

The work is structured in a way that both reflects my PhD journey and hopes to engage the reader. It is the result of an attempt to reconcile the demands of a postmodern stance and the academic requirements for a doctorate. Indeed, one could argue that to write a 'thesis' in itself is a very un-postmodern undertaking, as it seeks to fix meaning and create explanatory categories. Some chapters are more postmodern in their approach than others and much debate has happened over their inclusion. I hope that, reaching the end of the document, the reader will see the thesis clearly, yet in an acknowledgement that this theorising is not intended as a firm ontologisation. Postmodern writers are notoriously convoluted, obscure and some, like Deleuze and Guattari (1980), use a disorganised writing style in order to tear apart common sense assumptions and open up the possibilities of thinking differently. Writing is using signs, words, to represent concepts. There is no *true* meaning behind these words, only assumptions about them, which are challenged in postmodern writing. Above all, Gilles Deleuze, Félix Guattari and Jacques Derrida question established and rigid categories of thought, such as those created by philosophy. They see them as stifling and contrasting with the fluidity and chaotic nature of life. At first, Derrida himself rejected the possibility of writing a PhD thesis because the limits and structure required did not allow him to question the very foundations of philosophical thought (Collins and Mayblin 1996). Given these reflections, it seems that the conventional structure of a PhD thesis in introduction, background, methodology, method, results and discussion / conclusion is deeply at odds with the philosophy I adopt in doing this work. On the other hand, through much of my academic life so far, I am the product of a predominantly scientific and organised view of the world. As are the readers of this thesis likely to be. I need therefore to achieve a communication style that is understandable and hopefully engaging, while respecting postmodern thought. Therein lies my greatest dilemma in writing these words. The structure I have adopted reflects my journey, in that it starts in a very traditional way by establishing the current state of knowledge about quality of life.

A background section summarises current academic, philosophical and historical understandings of quality of life. It introduces MS as a tracer issue for long-term

conditions and places it in the context of the health services and quality of life measurements. The Schedule for the Evaluation of Individual Quality of Life (SEIQoL) is then introduced, as the quality of life measure used in the evaluation. As in my theoretical journey, postmodernism is only introduced then, with the insights it can bring in health, illness and the quality of life. The policy context to the work is then introduced; together with insights of the way in which quality of life may be approached in the media.

The theoretical framework for this work is then exposed explicitly and relevant postmodern terms detailed and explained. Following this, the structure of the thesis loses some of its conventionality. I introduce the texts to be examined and expose the frame of analysis. In a conventional piece of work, this would be referred to as a method section. However, much of it explains how and why 'method' does not belong to postmodern vocabulary and therefore does not sit easily in a postmodern thesis. A method is in itself a metanarrative - an all encompassing explanatory framework - in need of deconstruction. Rather, what 'method' may mean in a nomadic framework is explained and the various texts to be examined introduced. 'Text' is preferred to 'data' in an acknowledgement of the intertextual nature of thought.

The theoretical framework underpins the layout of the rest of the thesis. What follows is therefore a textual journey, rather than a result section, to provide the physical support to a nomadic approach to quality of life. This journey becomes the core of this thesis and hopes to engage the reader in dis-order, so that thinking about quality of life can be opened up to difference. Quality of life is conceptualised as a text in need of deconstruction. In the context of this thesis and using long-term conditions as a frame, it is conceived as being underpinned by five oppositional constructs. These are life and death, health and disease, dependence and independence, empowerment and disempowerment, and certainty and uncertainty. These concepts are deconstructed one by one and form a leading thread through the textual journey proposed to the reader. Interwoven in this deconstruction are the texts themselves, each offering a window through which quality of life in long-term condition can be observed. These texts both inform and are informed by the

deconstruction of oppositional pairs. Chapters resulting from conventional qualitative research are also alternated with those analysing the political and cultural background to their making.

The journey is followed by a reflection on the quality of life conceptualisations encountered, and what these may mean philosophically, methodologically and practically. These are proposed as possibilities, rather than statements of truth. As such, the reader is expected to assume his own interpretation of the journey and what that may mean for the quality of life of people with long-term conditions. The consequences that I propose from the journey are in themselves in need of deconstruction. This thesis is indeed the product of the time and space of its making and only vows to open up, rather than fix or close, meaning.

# Background

The overall aim of this section is to introduce the thesis in its interdisciplinarity. It looks at health, quality of life and media studies. It begins with an introduction of the current state of knowledge about quality of life and the different currents of thought that form its main conceptualisations. It exposes how historically, ethically and politically the concept has been used, introduces the state of knowledge about quality of life in MS and the way in which it was measured in this work. The policy context of the three service developments is then introduced, as well as the ways in which health, illness and quality of life can be conceptualised from a postmodern stance. The section then introduces media studies, in relation to health and quality of life, and concludes with clarification of where this study stands in relation to disability studies.

## Quality of life conceptualisations

Many reviews of quality of life exist, cataloguing existing measures (Bowling 2001; 2005) or offering a philosophical (Rapley 2003), social (Michalos 2004) or health related (Taillefer 2003) overview of the concept. Quality of life has a very powerful, if not pervasive, resonance in contemporary academia. This very popularity may be the reason for the current fragmentation in the literature, which displays controversies over issues ranging from the adequacy of quality of life as a scientific construct, to its meaningfulness or its relevance to social policy or health care (Kaplan and Bush 1982; Veenhoven 1996, 2002; Rapley 2003). Given this fragmentation and the fact that sociologists and health researchers tend to conduct their debates in isolation of each other (Michalos 2004), Cummins suggests that “the literature is now too vast for any individual researcher to fully assimilate” (Cummins 1997: 118). Hence this background section is selective. I take the reader through some historical, ethical, ontological and methodical territories occupied by quality of life. The term ‘territory’ is preferred here to ‘perspectives’, in reference to the

postmodern concept of territorialisation, which I introduce later in this thesis. This should not distract the reader from the content of the following paragraphs. These are inevitably and necessarily incomplete, but my hope is that they will provide an overview of the concept sufficient for the reader to engage with the rest of the thesis.

In the first of the following sections, I have mostly used pre-existing overviews of the concept by authors who themselves have conducted extensive reviews of the quality of life literature in order to trace its origins. The second section, which focuses on the ontological status of quality of life from different perspectives, presents both sociological and health related accounts of quality of life. This is done to reflect the interdisciplinary focus of this work. Eminent and prolific researchers in both fields were chosen to illustrate this. Three broad philosophical currents, which I illustrate with examples of recent research accounts, are then introduced. Measurement issues are then presented from a health care perspective, in congruence with the rest of this work.

**a. Historical, academic and ethical territories**

While concerns about ‘the good life’ date back to early Greek philosophy - Aristotle (384-322 BCE) wrote more than nine books enquiring into the nature of human happiness - it only appeared on the academic landscape in the early 1920s. The concept focussed on the general life of communities and was used to describe the quality of socially constructed life (Koch 2000). As part of this, Michalos (2004) traces the social indicators movement back to the mid 1950s. He describes a social indicator as a “social statistic that is supposed to have some significance for the quality of life” (Michalos 2004: 30) and is the editor of the journal *Social Indicators Research*. This was a period in which governments sponsored many forms of social programmes which needed to be evaluated (Land 2000). Thus, ‘quality of life’ appeared in the literatures of the political and social sciences as an antidote to public intoxication with purely economic measures of social welfare (Veenhoven 1996; Birnbacher 1999; Michalos 2004).

Cummins (1997) attributes the first association of quality of life as a characteristic of individuals and an indicator of national prosperity to a speech by President Johnson, in which he reported that progress “cannot be measured by the size of our bank balance... [but] by the quality of the lives our people lead” (Cummins 1997: 117). In 1978, Schin and Johnson attempted to conceptualise a causal model of happiness, based on an individual’s

biological, interpersonal and achieved resources; his assessment of various individual and communal needs; his self-actualising activities; and the perception of his life standing relative to other people and his past life experience (Schin and Johnson 1978: 487).

Twenty-six years later, members of the International Society for Quality of Life Studies still vow to develop a “grand accounting scheme” (Michalos 2004: 36) for quality of life. This would include social, environmental and economical variables as well as a measure of subjective well-being (Michalos 2004). Social indicators researchers generally appreciate the political relevance of their work (Veenhoven 1996 provides an example of this), but they are often dismissive of a poststructuralist reading of the social indicators movement (Cummins 2001).

Advocates of the eugenic movement in the United States introduced quality of life assumptions as a general clinical perspective early in the Twentieth century. The argument was that some people were so impaired that death was, for them, socially desirable. Lives with physical or cognitive challenges were seen as unworthy, a burden for the national economy and in many cases both socially undesirable and clinically avoidable (Koch 2000; Rose 2001). While the United States was an early leader in such a eugenic movement, it infamously reached its apotheosis in Germany during the Third Reich. There, the systematic killing of people with a variety of distinguishing traits was politically and socially promoted (Rapley 2003; Hatch 2005). Since World War II, judgements of the ‘worthy’ life have been replaced in health care by discussions of quality of life, often based on the assessment of an individual’s physical and cognitive attributes (Edlung and Tancredi 1985). Although the concept is by now commonly used in health related studies, it still meets a great deal of reserve. One such reservation is that the concept seems to be inherently dangerous, by potentially encouraging a grading of individual lives according to their measured quality (Hatton 1998; Birnbacher 1999). For example, the idea that it is



possible to quantify the future quality of life provides a rationale for antenatal genetic testing (Shakespeare 1998; Rose 2001), the selective abortion of particular foetuses (Kuhse and Singer 1985), for the provision of life sustaining treatment (Nord 1999), and in some cases, physician assisted suicide (Sheldon 2000). Cummins (1997) exposes the potential ethical problems that exist in population specific quality of life measurement scales:

A view that is limited to a population sub-group can restrict the view of what might constitute a high life quality for its members. Such definitions are shaped by the deficits of the groups to which they refer and, as a consequence, have been down graded to reflect the assumption of a lower life quality than normal. Such assumptions, however, are likely to be invalid. The huge literature on positive and negative affect... is consistent in its appreciation that each is independent of the other, such that people with serious disabilities may nevertheless describe themselves as happy, enthusiastic and excited about life (1997: 123).

Rapley (2003) reinforces this and highlights the tendency in the research community to impose quality of life variables onto respondent groups. He refers to this phenomenon as 'mainstream' quality of life research and argues that if quality of life is to be of benefit to the people whose life is studied, then researchers must shift to an emancipatory paradigm (Rapley 2003).

In health care, the quality of life movement was a symptom of uneasiness about a system that had previously judged its own merits exclusively in terms of functional aims and prolongation of life expectancy (Sullivan 2003). Edlund and Tancredi (1985) expose how, if sanctity of life remains the goal of medicine, its shortcomings left a void partly replaced by the notion and measurement of quality of life. Sullivan (2003) describes the turn to patient-centred outcomes in health care as starting around 1949. He describes this movement for the inclusion of patient-centred outcomes as challenging the scientific hard core of medicine. Up until then, purely clinico-pathological observations were driving medicine as an objective and detached scientific enterprise (Edlung and Tancredi 1985). Edlung and Tancredi (1985) assert that this shift in ideological perspective eroded the prerogative of the health care professional to determine care unilaterally. However, in this climate, health related quality of life measures had to prove their scientific robustness and validity, in order to gain legitimacy.

Michalos (2004) highlights the difference in approach between the social and health movement towards the study of quality of life. For social indicators researchers, he contends, health is one determinant of people's overall quality of life. While some health-related quality of life researchers recognise the multidimensional characteristic of quality of life (Bowling 2005), their general assumption is that health is its most important determinant (Michalos 2004). This may be linked to the difference in focus, as social indicators researchers seek to model quality of life in order to inform policy (Veenhoven 1996; Michalos 2004), while the health related quality of life movement was borne out of a desire to broaden outcome measures for health services (Prutkin and Feinstein 2002; Sullivan 2003; Bowling 2005).

#### **b. Ontological territories**

Quality of life is often used interchangeably with happiness, life satisfaction or subjective well-being. Happiness has been assimilated with subjective well-being and described as an affective construct (Veenhoven 2000; Sirgy 2002; Bowling 2005). Life satisfaction, on the other hand, is viewed as a cognitive conceptualisation of happiness (Sirgy 2002), or an overall assessment of one's life (Bowling 2005). Bowling (2005) distinguishes between subjective well-being, as comprising "dimensions of happiness, life satisfaction, morale, self-esteem and sense of coherence" (2005: 6), and quality of life which "is about the goodness of life" (2005: 7).

There is no universally accepted definition of quality of life (Rapley 2003). Some focus strictly on health and physical function (Mendola and Pelligrini 1979), others integrate the notion of happiness (Zumbo and Michalos 2000; McKevitt et al. 2003) or well-being (Olthuis and Dekkers 2005), socio-economic status (Sherwood et al. 1997), living environment (Furuset and Walcott 1990) or social support (Haug and Folmar 1986). In health care, reintegration to previous activities has been used as an approximation to quality of life (Wood-Dauphinee and Williams 1987). Some authors acknowledge and establish the multidimensional and dynamic characteristics of the concept (Bowling and Gabriel 2003; Gabriel and Bowling 2004).

Ontologically, quality of life is broadly perceived differently by the sociological and the medical traditions. Sociologists concern themselves with definitional issues according to which health is a determinant of quality of life, but not a necessary condition of it (Michalos 2004). Quality of life in health care, in contrast to this, has been mainly concerned with measuring the outcome of services or intervention (Bowling 2005). According to this view, and following the WHO definition, “health is a state of complete physical, mental and social well-being” (WHO 1946), health derives from well-being, rather than being one of its components. Philosophically, three different schools of thought can be identified: Perfectionism, Hedonism and Preference Theory (Brock 1993; Sandøe 1999).

### ***Perfectionism or Ideal theory***

In the *Nicomachean Ethics*, Aristotle (1934) gave the classic formulation of perfectionism. According to Aristotle, every living being has an essence, which sets a goal for that being. Few philosophers today would entirely adopt the Aristotelian conceptualisation of human nature. Quite a few however, accept the key idea that there are a number of substantial human characteristics, and that one has to achieve in at least some of those to have a ‘good life’. This has also been referred to as the ‘need’ approach to quality of life measurement (Häyry 1999), which in some measurement scales has been based on Maslow’s (1987) hierarchy of human needs (Griffin 1986; Sirgy 2002). Perfectionism appeals to widely shared intuitions about what constitutes a good life, such as having health, wealth and social support (Brock 1993). In medicine, ‘quality of life’ was introduced as a supplement to traditional biological and functional information about patients, with the underlying idea that medicine should care about the person as a whole and not just the sick body (Musschenga 1997; Prutkin and Feinstein 2002; Sullivan 2003).

### ***Hedonism***

Jeremy Bentham (1748-1832) gave the classic formulation of Hedonism and claimed that governments’ primary purpose should be to ensure the greatest amount of happiness to the greatest number (Sirgy 2002; Michalos 2004). This view suggests that quality of life exists in the presence of pleasant mental states and in the absence of painful or unpleasant ones (Brock 1993). The use of Quality Adjusted Life Years

(Kaplan and Bush 1982) as indicators of health gain in health service resource allocation is frequently defended on such utilitarian grounds, in that they appear to facilitate the greatest health gain for the greatest number (Bowling 2001). Debates have long since been raging between the proponents of such utilitarian measures in health care and their opponents, who reject this majoritarian bias (Bowling 2001).

Hedonism claims that quality of life has a specific content and in that, is similar to perfectionism. However, quality of life is defined in terms of mental states and since mental states are given through subjective accounts, there is also a clear connection with the preference theory (Sandøe 1999). Michalos (2004) provides an example of this in asserting that quality of life can be measured and compared directly using indicators such as satisfaction with family relations. Gabriel and Bowling (2004) endorse a similar view in arguing that societies live according to a common core of values that influence people's quality of life both directly and through their subjective perception of them. They report a qualitative study of 80 older people's quality of life in Britain, using semi-biographical interview techniques. They conclude that for these people, quality of life was related to:

Having social relationships, help and support; living in a home and neighbourhood that is perceived to give pleasure, feels safe, is neighbourly, and has access to local facilities and service including transport; about engaging in hobbies and leisure activities (solo) as well as maintaining social activities and retaining a role in society; about having a positive psychological outlook and acceptance of circumstances which cannot be changed; about having good health and mobility; and finally having enough money to meet basic needs and to enable people to participate in society and to enjoy life, and to retain one's independence and control over life (Gabriel and Bowling 2004: 689).

While their approach is based on the subjective nature of quality of life, their overall aim comes close to Michalos' (2004) in providing a detailed account of quality of life components. They conducted their study with the development of a model to inform quality of life measurement scales in mind (Gabriel and Bowling 2004).

### *Preference Theory*

The obvious antidote to perfectionism is the preference theory (Brandt 1979; Hare 1981; Nordenfelt 1994; Sumner 1996). Here, quality of life is defined in terms of

life satisfaction: a good life is one in which the person gets what he or she wants (Brock 1993). This has also been referred to as the 'want approach', developed by Calman (1984) in particular:

A good quality of life can be said to be present when the hopes of an individual are matched and fulfilled by experience. The opposite is also true: a poor quality of life occurs when the hopes do not meet with the experience (1984: 124-125).

In other words, Calman's claim is that quality of life can be maintained and improved when an individual gets what he or she *wants*. However, this does not simply mean that the person's hopes and expectations are registered and then fulfilled. Calman points out that the goals set by the individual must be *realistic* and that the gap between reality and expectations can be narrowed "by making expectations more realistic" (Calman 1984: 125), which does not mean denying hope. Rather, it could mean encouraging the individual to develop and grow in other ways. Thus, according to this view, it is equally possible to improve a person's quality of life by lowering his or her expectations, as it is to achieve the same effect by enabling the expectations to be fulfilled. This is very closely related to the currently influential Multiple Discrepancies Theory (Michalos 1985), where unsatisfied wants are qualified as discrepancies. Such 'gap' theories form the conceptual backdrop to many health related quality of life measures (Bowling 2001).

### **c. Epistemological territories**

Quality of life has been defined in population wide, objective, societal terms, as well as in individual terms. Social indicators researchers have long established the validity of reported well-being (Andrews and Crandall 1976) and still stress its importance for social policy (Veenhoven 2002). While some researchers still engage in the debate about the values of objective and subjective measures of quality of life, most accept its multi-dimensionality (Veenhoven 1996; Cummins 1997; Michalos 2004; Bowling 2005). Beckie and Hayduck (1997) argue, however, that this is confounding the multidimensionality of the concept with its multitude of causal factors. According to them, quality of life is a one-dimensional construct that should

be measured by direct, open-ended questions such as “how do you feel about your life as a whole?” (1997: 27).

Cummins (2003) proposes that quality of life is a ‘hard wired’ homeostatically controlled brain state. For him, subjective well-being is “a dispositional brain system that acts to keep each individual’s well-being within a narrow positive range” (2003: 5). This is held at approximately 75% of a maximum scale of life satisfaction. This theory is representative of Western psychology, in that it proposes a biological explanatory system for all human experiences (Rapley 2003). Sirgy (2002) gives a comprehensive review of psychological research in quality of life. Rapley (2003) asserts that such psychological insights have formed the most influential formulations of quality of life. These theories are in direct opposition with phenomenological or sociological understandings of quality of life.

Both Benner (1985) and Draper (1997) have explored the nature of quality of life from a Heideggerian perspective. Draper (1992) suggests that if disease is a pathological alteration in physiology and illness a disease subjectively experienced, then ‘quality of life’ could bridge the gap between the two. Following this view, ‘life’ gives context to isolated scientific facts, while ‘quality’ has overtones of “the personal, the subjective, and even the moral” (Draper 1992: 969). From a subjective or Heideggerian perspective, there can therefore be no ‘objective’ understanding of quality of life, uncontaminated by one’s experiences. The way in which one lives one’s life and the way in which one understands it, are mutually determining. However, developers of health related quality of life measures seldom concerned themselves with such hermeneutical approaches (Bowling 2001).

#### **d. Methodical territories**

The main theoretical framework underpinning quality of life measures in health care derive from Maslow’s (1987) hierarchy of human needs and from social-psychological models that emphasise autonomy, control and self-sufficiency (Fry 2000). These may overlap with models of subjective well-being (Andrews 1986),

‘want’ approaches, such as the one developed by Calman (1984), and phenomenological models of the individual’s perception of their unique life circumstances (O’Boyle 1997). Bowling (2001, 2005) provides comprehensive reviews of quality of life measurement scales in health care.

Since its early days, research in health and quality of life has evolved and most measurement tools now encompass subjective and objective elements (Smith 2000). Measures of quality of life can be domain or age specific. They can be structured, in that respondents are given a set of questions with pre-coded answers, or relatively unstructured, with open-ended questions and no pre-coding. Some measurement tools are said to focus on individual or health related quality of life, some of these being generic or disease-specific. Examples of these are given in the following paragraphs.

### ***Health-related quality of life measures***

Broadly speaking, there are two types of health related quality of life measures: those that are specific to diseases and those that are said to be generic (Bowling 2005). Michalos (2004) argues strongly against the use of such measures, on the grounds that they obscure the impact of health on quality of life in assuming their correlation, which, he demonstrates, does not exist. Prutkin and Feinstein (2002) studied the evolution of quality of life measurement in medicine and emphasise how health related quality of life measures were developed by medical scientists “to avoid including non-medical components” and how they are “expressed as a combination of functional status and symptoms related to specific diseases” (2002: 88). This is corroborated by other authors, all highlighting the unfortunate confusion between measures of health status that allow the experience of symptoms or treatment to be recorded and quality of life (Bonomi et al. 2000; Testa 2000; Cox 2003; Sullivan 2003). Quality of life in relation to health is often implicitly, rather than explicitly, defined from a functionalist perspective of society, which relates to the ability to perform activities of daily living and fulfil role obligations (Bowling 2001). Bowling (2001) defines health related quality of life as

Optimum levels of mental, physical, role (e.g. work, parent, carer, etc.) and social functioning, including relationships, and perceptions of health, fitness, life satisfaction and well-being. It should also include

some assessment of the patient's level of satisfaction with treatment, outcome and health status and with future prospects (2001: 6).

The theoretical framework of health related quality of life, then, is largely based on a multidimensional view of health along the lines of the WHO's definition of health (1946). Generic health related quality of life measures are often used when comparison between different conditions is required, which would not be possible with condition-specific measures. The SF-36 (Ware 2006) is a well-known and widely used generic health quality of life measure. Researchers have used it to assess quality of life in older people (Michalos et al. 2001) and to produce population norms (Bowling 2005). Such generic measures have been criticised for being insensitive to relevant clinical outcomes and McKenna and Whalley (1998) have argued that their uses in health care are bound to diminish as more disease specific measures are developed.

Disease-specific quality of life measures aim to be more clinically significant for a particular condition and are often used to measure outcome for particular treatment or interventions (Bowling 2001). These are clearly specific to diagnostic groups, but are often criticised for being too narrow in focus. Bowling (2001) gives an extensive catalogue of disease-specific quality of life measures and presents them by diagnostic group, in cancer related scales, those for psychiatric, respiratory, neurological and rheumatological conditions, and cardiovascular diseases.

### *Individual quality of life measures*

Individual quality of life measures avoid pre-determined life categories and take into account an individual's perspective. They are seen to be more philosophically grounded and less influenced by utilitarian concerns than their health related counterparts (Bowling 2001). The Schedule for the Evaluation of Individual Quality of Life (SEIQoL) (O'Boyle et al. 1993) is one such measure.

The SEIQoL assesses patients' judgements about what they value in relation to their own quality of life (O'Boyle 1994). It is based on the basic propositions that quality of life should be assessed by self-report and that a person's judgement is constructed from an assessment of his or her level of satisfaction in discrete domains of life that



they consider important (O'Boyle et al. 1993). O'Boyle (1997) proposes that health care services should be measured from the perspective of the patient, in terms of how services make a difference to day to day living, therefore complementing traditional measures based on disease status and mortality. He further suggests that quality of life data could provide information on the effectiveness of medical care and ways to improve it and, in this, contribute to health policy (O'Boyle 1994).

The SEIQoL has by now been used in people suffering from peptic ulcer disease and irritable bowel disease (McGee et al. 1991); osteoarthritis (O'Boyle et al. 1992); AIDS (Hickey et al. 1996); cancer (Broadhead et al. 1998; Waldron et al. 1999); cystic fibrosis (Ramström et al. 2000); stroke (Smout et al. 2001); multiple sclerosis (Lintern et al. 2001); mental illness (Prince and Gerber 2001); amyotrophic lateral sclerosis (Clarke et al. 2001; Bromberg and Forsheew 2002); people with leukaemia and lymphoma (Montgomery et al. 2002); people with End Stage Renal Failure (Pugh-Clarke et al. 2002); caregivers of people with dementia (Coen et al. 2002); young people with diabetes (Wagner 2004) and people with Chronic Obstructive Pulmonary Disease (Lhussier et al. 2005) to name a few.

Bowling (1995) used the SEIQoL in a sample of the general population, in a bid to build up a body of knowledge based on population norms, for use in health services research. 40% of the people surveyed reported a longstanding illness and people who assessed their health as 'not good' were most likely to mention effects on their own health as the first most important thing in life generally. This contrasts with the fact that in people who have been diagnosed with a long-term condition, no correlation has been found between functional status and important life areas (Lhussier et al. 2005). Rather, general health seems to have an indirect impact on quality of life, through the level of health satisfaction (Michalos et al. 2001; Michalos and Zumbo 2002).

## **Multiple sclerosis**

MS, like many long-term conditions, can have major implications in a person's everyday life and is often seen as the cause for poor quality of life (Miller and Dishon 2006). MS is a long-term neurological disease with onset typically in early adult life and with a peak of incidence at about 30 years of age. The clinical course and the signs, symptoms and degree of impairment associated with MS are highly variable (CSP 2001; Swann 2006). It can take four principal forms and courses and an individual's MS trajectory may evolve between them (Joy and Johnson 2001; Swann 2006):

- Benign MS starts with a small number of mild attacks followed by complete recovery.
- In primary progressive MS, symptoms gradually develop and worsen over time.
- Relapsing-remitting MS is the most common type, which about 85% of people present with at onset. Relapses tend to be unpredictable and their cause is unclear. They can last for days, weeks or months and vary from mild to severe.
- Many people who start out with relapsing-remitting MS later develop a form known as secondary progressive MS. This means that the impairments progressively worsen between attacks, or that the cycle of attacks followed by remissions is replaced by a steady progression of impairments.

This uncertainty about the course of the disease, which means that people move in and out of impairment, makes it a particularly relevant tracer issue for long-term conditions as conceptualised in this project.

Freeman and Thompson (2000) found that despite services for people with MS figuring high on the policy agenda of the government, "wide and unacceptable variations in the provision of outpatient and community services remain a fundamental problem for people with multiple sclerosis" (2000: 732). In a later publication, the same authors advocate the rigorous evaluation of rehabilitation interventions such as physiotherapy (Freeman and Thompson 2001), while broadening the research methodology used to explore the experience and views of

people with MS, their families and the professionals who work with them. In a study of the expectations of people with MS regarding health services, Somerset et al. (2001) found considerable evidence of diversity in the range of requirements for services. The needs and preferences that were unmet related to the desire for specific information and for the services of particular health professionals. In a qualitative investigation of multiple sclerosis and quality of life, the same authors (Somerset et al. 2002) highlight that aspects of life that can contribute to the well-being of a person with MS can be divided into those that are relatively unavoidable and others which could potentially be affected by intervention from health or social services. They advise that, by establishing a partnership with the person who has MS, professionals and carers are more likely to bring positive support and, as a result, may help them gain a greater sense of personal control and autonomy (Somerset et al. 2002). The SEIQoL (O'Boyle et al. 1993), when compared to other quality of life measures, has been found to come closer to measuring the "subjective and dynamic elements likely to have major influences on the quality of life of people with MS" (Lintern et al. 2001: 377).

## **Policy context**

Over the past few years, a new emphasis has emerged in policy documents within the UK National Health Service (NHS) over the involvement of people in the delivery of care. In 1999, the White Paper *Saving Lives: Our Healthier Nation* (DoH 1999) initiated this movement by recognising people's ability to make decisions about their own health. A year later, a detailed *NHS Plan* (DoH 2000) was launched for the application of the ideas set out in the White Paper. This described patients as being disempowered in an over centralised health care system. It promised an investment in NHS facilities and personnel so that care could be organised around people's needs.

*The Expert Patient* was published in September 2001 (DoH 2001a), advocating the introduction of lay-led self-management training programmes as part of a wider strategy to improve the management of long-term conditions. In the autumn of 2001,

*Shifting the Balance of Power: Securing Delivery* was published (DoH 2001b), followed in January 2002 by *Shifting the Balance of Power: The Next Steps* (DoH 2002). These set out the way to empower front line staff and service users. They advocate changes in organisations and attitudes, so that front line staff are supported to develop their practice and increase patient centredness. Concurrently, the World Health Organisation published *Innovative Care for Chronic Conditions* (WHO 2002a), which recognises the growing challenge of long-term conditions internationally. This report highlights the shortcomings of current systems of care, which tend to be organised around acute episodes of care with sporadic follow-up systems, poor community services and patients who are not fully involved in their own care. In 2004, *Putting People at the Heart of Public Services* (DoH 2004) added to the national move by putting the emphasis on offering “person centred and personalised” health services. This document highlights that although the concept of person centredness applies to all patient groups, this should particularly be the case for people with long-term conditions and older people.

The National Service Frameworks (NSF) were introduced by the new Labour government in 1997 and detail clinical guidelines and ideal service models which specify the conditions of care delivery (Checkland 2004). Checkland (2004) describes the NSFs as embracing a ‘scientific-bureaucratic’ approach that mirrors current changes in the NHS about the conceptualisation of health and disease in a population based, or public health, approach. That is, they translate evidence generated chiefly through randomised controlled trials, into sets of normative standards that are then accepted as ‘gold standards’ (Checkland 2004). The NSF for Long-Term Conditions (NSF for LTC) was published in March 2005 (DoH 2005). It was developed following recognition of the limitations of such previously used evidence appraisal systems, which favoured quantitative experimental research. The NSF Expert Reference Group developed a new typology for the appraisal of evidence, which “acknowledges the importance of expert opinion from users, carers and professionals, as well as encompassing a broad range of research designs” (Turner-Stokes et al. 2006: 91). It is the first time in the development of NSFs that such an emphasis is put on user perspectives. For this reason, as well as the funding structure attached to it, it has been described as a ‘new style’ NSF (Turner-Stokes

and Whitworth 2005). It follows the *NHS Improvement Plan: Putting People at the Heart of Public Services* (DoH 2004), which sets a strategic model for the management of long-term conditions through self-care, disease management and case management. It also builds on *Supporting People with Long-Term Conditions – An NHS and Social Care Model to Support Local Innovation and Integration* (DoH 2005), which introduces new models of service delivery for people with long-term conditions. The NSF aims to pave the way for their implementation in practice. It focuses on neurological conditions, but its recommendations are said to apply to all long-term conditions.

As part of the *NHS Plan*, the National Institute for Clinical Excellence (NICE) was set up in order to produce evidence on which to base practice nationally. A NICE guideline on the management of MS was published in 2003 (NICE 2003). It recommends that:

All health services and service personnel ... should recognise - and respond to - the varying and unique needs and expectations of each person with MS. The person with MS should be involved actively in all decisions and actions (2003: 5).

This is in line with the other policy documents described and sets the political scene behind the service developments evaluated as part of this project. This broad move towards more inclusion of people with long-term conditions in general, and people with MS in particular, in both their own care and the development of services gives this project particular timeliness and relevance.

## **Quality of life in the media**

### **a. The Mass Media**

The Mass Media are part of our everyday life and help to express as much as to reinforce social values. For example, the idea that the advent of television marked a change in the social order has become received wisdom:

It is a truism that Mass Media have a decisive political, social and cultural importance. Mass Media have lost and won wars (Vietnam and the Gulf), removed and elected political leaders (Nixon and

Berlusconi)... Mass Media are also engaged in the production of the fabric of everyday life as they organise our leisure time, shape our social behaviour and provide the material out of which our very identities are constructed in terms of class, role, nationality, sexuality, and distinction between 'us' and 'them' (Torring 1999: 210).

Karpf (1988) asserts "health and medical programming plays a significant role in shaping public debate and the climate of opinion" (1988: 230). The media suggest patterns of proper and improper behaviour and deliver ideological messages (Kellner and Durham 2001). Television in particular, has been described as "a primary source of the common information and images that create and maintain a world's view and value system" (Gross 2001: 407). What is seen on the television or cinema screen relates to the wider structures of society and produces particular forms of knowledge and positions for viewers. So drama episodes or documentaries for example have a certain 'shelf life', in that they reflect what is acceptable or topical at the time of production. White (1992) argues:

Because of this social and historical specificity, artefacts express and promote values, beliefs and ideas that are pertinent to the context in which they are produced, distributed and received (1992: 163).

A postmodern vision of society acknowledges the power of discourse, but only in interaction with the viewer's agency. Media literacy and a renewed respect for the abilities of viewers, mean that few would subscribe to the idea of people blindly associating smoking with cowboys, for example. However, these connotations have their place in understanding the ways in which cultural meanings shift and manifest themselves. People form understandings about quality of life in long-term conditions through documentaries or news events. The case of baby Charlotte Wyatt, which made the news in February 2005, was one such event. After having been resuscitated three times the decision was made, in the name of her prognosticated poor quality of life, not to resuscitate her again. Mr Wragg has recently admitted killing his son, who was suffering from Hunter Syndrome and described it as a 'mercy killing', because of his son's poor quality of life. While these cases are extreme, they undoubtedly put debates about health, disease and life quality at the forefront of the viewers' minds. People know about these stories because they have read or watched documentaries about them. Yet only a small proportion of audiences will have had a direct experience of Hunter Syndrome: they negotiate a

world that is, for a great part, shaped by media images. So television, among a range of media, is involved in the selective provision of social knowledge, through which we perceive the lived realities of others:

Television has its place in the interplay between individuals' ongoing construction of identity on the one hand and the general 'macro' functions of society on the other... television is, as the most central of all media, part of the very fabric of everyday life (Gripsrud 2002: 25).

Following Gripsrud (2002), this study would be incomplete without an inclusion of some media artefacts and some television programmes in particular. If television plays a role in the construction of our identities, it inherently influences how we come to think about our quality of life with long-term conditions. However, while the influence of the media in people's life is regularly scrutinised, the representation of quality of life in the media is not. This trend reflects what King and Watson (2005) have observed in health studies:

Whilst media studies as a 'discipline' is now well established (if not always well regarded), there has been relatively little so far that has attempted to bring together ideas about the ways in which narratives of health and illness get shaped by, and echo in, various media genres (2005: 2).

In its postmodern outlook, this study takes an interdisciplinary focus and attempts to bring together health, quality of life and media studies in order to highlight congruent discursive practices.

## **b. Re-presentation**

According to Baudrillard (1983), the postmodern world is one in which a series of modern distinctions, for example those between the real and the fictional, are broken down. He points to the overload of information provided by the media, which confronts us with an endless flow of images and representations, so that the boundaries are blurred between real life and its representation on television. He refers to this phenomenon as 'hyper-reality'. The prefix 'hyper' means 'more real than real', since the real is copied from a mediated reality itself artificially produced as real. This simulated postmodern world is a place where life somehow seems less real, less sharp and less full than its representations on television. Examples of this are CDs with the recorded scratchy sound of vinyl, reality television, Disney theme

parks, surround sound home cinema systems or the computer generated images that show people their projected ageing appearance. These are all attempts to increase the feel of reality, but they are all simulations; they are hyperreal, rather than “really real” (Ward 2003: 75). Like Gripsrud (2002), Baudrillard (2002) characterises television as the predominant global medium of the 21<sup>st</sup> century.

Media studies have traditionally been classified as those focussing on media artefacts and those which take for focus the experiential aspect of interacting with media. Although this dialectic may be problematic (Hansen 2006), in this thesis the focus will be on media artefacts. Hansen (2006) demonstrates that

media has always been correlated with the living... all media mediates is life, and that human life is mediation, that is, the concrete actualisation of the living via exteriorisation in an environment, in a medium (2006: 301).

What emerges from this is the necessity, in studying media artefacts, to consider their production as an inherent quality of humans. In this, representations of long-term conditions are not only re-presentations that stand apart from society. They have, over time, evolved with, as much as they have informed, people’s conceptualisations in a dialectical relationship. Thus, I adopt the use of media artefacts as focus in this study, rather than the lived experiences they produce, in the acknowledgement of this dialectical relationship. Artefacts are scrutinised for the signifiers of long-term conditions they may contain and the discursive practices that support them.

### **c. Body Images**

Postmodern society sees the upsurge of a utopian model of bodily perfection and cure. One has to look no further than television appeals to find a cure for various birth ‘defects’, impairments and illnesses. Such recent television programmes as, for example, the *Body Shock* series (on Channel 4), where extreme cases of tumour are presented and cured, are examples of this. Others, such as *Ten Years Younger* (Channel 4), are overtly about the perfect body, which has to look younger, better, trendier and fitter. In contrast to this, Wilde asserts:



Disabled people have been portrayed [in the media] in an individualistic manner within a medical model, which emphasises personal rather than social pathology (2005: 67).

Figures with impairments are often portrayed as predictable and often temporary characters. They are regularly cast as “victims, deviant, foolish and in contexts of violence” (Wilde 2005: 67).

Wilde (2005) conducted a study of the effect of viewing ‘soap operas’ on the viewers’ attitude towards impairment and disability. She demonstrated how people with and without impairments relate differently to the models of disability proposed in soap operas. Generally, people seemed to focus on the micro-narrative structures of the stories, often without a questioning of the meta-narrative represented. “Normality seems to be the most crucial micro-narrative of the soap opera, structuring macro-narrative discourses of disability, gender and sexuality” (Wilde 2005: 81). In her data, participants widely associated characters with impairments with narratives of cause and effect. For example, it was a common observation that ‘bad’ male characters had accidents resulting in impairments until they underwent moral reform. These story lines were seen by some participants as delivering a discriminatory moral discourse that did not stimulate multiple or resistive readings. Wilde (2005) concludes:

It seems that gaining pleasure from soap opera texts is incompatible with disability and impairment identifications... images of disabled characters return disabled viewers to an unachievable phantasy of normalisation (2005: 83).

Cheu (2002) studied the representation of disability in futuristic films. He postulates that disability should be present in futuristic films and demonstrates its representations. In the three films he studies - *Blade Runner* (1982), *Gattaca* (1997) and *The Matrix* (1999) - disability is figured through the minority population in technologically advanced societies: *replicants*, *de-gene-rates*, and *unfreed humans*. Cheu (2002) demonstrates that if disability is conceptualised as a social construction, rather than situated solely in bodily impairments, then the concept of cure becomes redundant. He states:

If you do not believe there is a disability, if you do not believe there is anything that needs to be ‘cured’ or genetically prevented - that

disability is indeed little more than a social construction - then you will likewise be freed from the need for cure (Cheu 2002: 209).

### **Disability and long-term conditions**

The management of long-term conditions is designed to prevent impairments and, as such, this thesis has much to do with disability studies. Its focus is, however, at once broader in concerning itself with the moments preceding impairment and more narrow, in excluding learning disabilities or congenital conditions, for example.

What is often understood by disability is a state of affair, in which the person is unable to perform some activities at any *point in time*. Lutz and Bowers (2005) describe how the current models of disability in the literature do not adequately capture the complexities of people's personal experiences of living with impairments. The medical model of disability has been described as an example of a culture of metanarratives, born out of modern binary thought processes (Corker and Shakespeare 2002). In this medical or individual model, disability is understood in terms of tragedy or deviance and on the assumption of weakness that needs to be adjusted. The social model conceptualises disability as separate from impairment and focuses on the elimination of prejudices, oppression and barriers, which prevent people with impairments from participating in society. The two perspectives are often mutually exclusive and lessen each other's significance (Imrie 2004). Shakespeare (2005) defines disability as "an interaction between impaired bodies and excluding environments" (2005: 147). A focus on such an interaction is seen by some as crucial in the development of a non-reductive and non-essentialised understanding of disability (Imrie 2004). Also recognising the need for a more integrated approach, the WHO developed the International Classification of Functioning, Disability and Health (ICF) (WHO 2002b). The ICF "attempts to achieve a synthesis, in order to provide a coherent view of different perspectives of health from a biological, individual and social perspective" (2002b: 20). However, some authors argue that it lacks conceptual specification and development, in particular in relation to impairment (Imrie 2004). Others argue that it remains rooted in a functionalist paradigm (Lutz and Bowers 2003).

However, the debate of whether the cause of a bodily inability sits in the impaired body, in its societal environment or in a dialectical relationship between the two, is beyond this work. So are, in spite of their importance and relevance to this work, the ideological battles of the disability movement. Rather, it is life in the *longitudinality* of a long-term condition, in which one may move in and out of impairment and disability that is of interest here. More accurately, this thesis focuses on those who live with the prognosticated possibility of impairments. For clarity in the terminology in this thesis, as in the social model of disability, when reference is made of bodily experience, ‘impairment’ will generally be the preferred term. When the context will be explicitly about one’s environment and its barriers, the term ‘disability’ will be preferred.

The World Health Organisation’s (2002a) definition of long-term conditions includes “non communicable conditions; persistent communicable conditions; long term mental disorders; ongoing physical / structural impairments” (2002a: 12). Long-term conditions are persistent, chronic and ongoing. They evolve and their course and effect may vary from one person to the next and take them through many bodily tribulations. It is this longevity and the changeability of bodily possibilities that is often assumed to have a negative and lasting effect on quality of life.

### **Postmodernism, health, illness and the quality of life**

There is an inherent sense of fluidity and open-endedness in postmodernism, which makes it resistant to concise definitions. In spite of this, there seems to be general agreement in the literature on a few basic traits, which share an implicit sensitivity for the complexity of the social world (Morris 1998; Corker and Shakespeare 2002; Appignanesi et al. 2003):

1. The postmodern era coincides with the rise of late consumer capitalism. This represents a shift from steel-and-concrete industrial productions to the culture of consumerism. In this climate, we have become the consumers of health care, which is now a heavily marketed product.

2. Postmodern thinkers regard all knowledge as historically and culturally contingent. Even the most accurate science does not provide pure facts, but reflects time and context-specific political and social desires. This is linked with a rejection of meta-narratives and a critique of Enlightenment assumptions, especially those about 'reality' or 'truth'.
3. Experience, for postmodern thinkers, is always mediated by organised discourses. They focus on a de-centralisation of the individual and the social world, often through a focus on culture, language and discourse.
4. Postmodernists derive their analysis from an ontological emphasis on uncertainty, instability, embodiment and the non-essential nature of things.

Frank argues that: "The postmodern experience of illness begins when ill people recognise that more is involved in their experiences than the medical story can tell" (1996: 6). In Frank's version, 'modern' and 'postmodern' denote of two different ways of living with illness: a modern style, in which people accept the medico-scientific narrative, and a postmodern style, in which patients reclaim power as creators of their own distinctive stories. Morris (1998) distinguishes between 'disease' as an objective biomedically based concept and 'illness', as the subjective experience of the patient. In the first concept, the mechanic of the human body has become dysfunctional and is in need of repair. In the latter, Morris sees the person as "no longer merely a bundle of symptoms reported by an unreliable and subjective ego" (2000: 39).

Clarke et al. (2006) characterise the turn from modernity to postmodernity as a turn from medicalisation to biomedicalisation. They describe this as a shift from the control over an external nature, to a harnessing and transformation of internal nature. The scope of this biomedicalisation process, they assert, includes

A commodification of health, the elaboration of risk and surveillance..., diagnostic tests and treatment procedures. This includes the production of new social forms through "dividing practices" that specify population segments such as risk groups (Rose 1994). These risk groups are to be given special attention through "new assemblages" (Deleuze and Guattari 1987) of spaces, persons, and techniques for care-giving (Clarke et al. 2006: 165).

From a postmodern perspective, health is something that coexists with illness. This rests on the postmodern rejection of the mostly binary thinking that supports modernist conceptions of health and illness. Postmodern culture offers a vision in which health can be redefined as the manner in which we live well despite our inescapable illnesses, disabilities and trauma (Frank 1996). Morris (1998) reinforces this and asserts that “complete well-being is a fantasy borrowed from modernist utopian fiction” (1998: 248). A postmodern paradigm takes our attention away from the individual as an autonomous subject, to the ways in which it is constructed through different discourses. Long-term conditions have so far been conceptualised mostly through a modernist functionalist health care discourse, in which the body has a ‘problem’ that requires fixing (Lupton 1995).

The medical model has gained authority through its claim of moral neutrality (Kimsma and Van Leeuwen 2005) and produces a discourse in which healthy lifestyles and practices of amelioration of the body are associated with positive self-identity (Williams 2000). Through this model, patients are not responsible for their disease, but rather victims in need of care. Critics of this medicalisation movement, such as Zola (1973), saw it more as an expropriation of the health of individuals. According to this critique, diseases become social constructs and, as Kimsma and Van Leeuwen state: “life is a series of medical phases with medically defined threats and therapies” (2005: 561).

Deconstruction is meant to unearth existing discourses that shape an object of study (Goodley and Rapley 2001) and highlight the historical assumptions that delimit a field of knowledge. Generally, as illustrated earlier, quality of life has been dominated by the social indicators movement and by utilitarian economic considerations. In health care it is conceptually dominated by the paradigms of medicine, psychology and social work. This is what Rose (1991: xiii) called the “psy-complex”, in which practitioners create discursive truths that serve to inform and govern human subjects in late Capitalist societies. The quality of life movement qualifies as one such discursive practice and is symptomatic of the past 50 years in the Western world.

Rapley and Ridgway (1998) highlight the discursive underpinnings to the quality of life movement and situate it as part of a 'quality revolution' in western societies. They state: "the notions of 'quality' and 'customer satisfaction' have come... to occupy a central position in the discourse of commercial, professional and public life" (1998: 452). Following this, quality of life constructs cease to describe established realities through scientific neutrality, but rather actively shape the social world and people's place within it. They highlight that while quality of life has been readily adopted as a benchmark for quality services for people with learning disabilities, it emanates from hard entrepreneurial and managerial political discourses (Rapley and Ridgway 1998). This might provide grounds to think that it may also be the case for the health services more generally.

This section has set the scene for the thesis, in summarising current quality of life conceptualisations, both in health care and in the wider social indicators movement. It shows the broad trajectories that MS can take and gives a research account of health care service provision for people with MS. The section also provides a brief overview of the current health care policy context, with its emphasis on patient centredness and patient involvement. It then exposes how we generally access a mediated hyperreality about quality of life in long-term conditions, and how our understanding is both shaped by and echoed in this mediation. This takes a utopian model of bodily perfection for emphasis, one that does not account for the possibility of illness. The section then moves on to take a distinguishing stance between disability and long-term conditions.

The last paragraph is an introduction to postmodernism as a broad movement and to what it may mean for the study of health, illness and the quality of life. While this serves as an introduction to the following section, in which I will expose the theoretical framework for this work in more detail, it also concludes this background. It highlights the discursive underpinning of the medicalisation of the ill body and presents the possibility of a discursive production of quality of life. It highlights the blurring of boundaries, for example between health and illness, possible in postmodernism, and that is central to this thesis. These final paragraphs come in opposition to much of the rest of the background and expose the possibility of a different stance than one that adopts definitional categories for quality of life and long-term conditions. As such, it establishes the need for this thesis, as if quality of life has been an essentialised object of study for centuries, a consensual definition is yet to be produced. An anti-essentialised stance, in which one blurs boundaries between long established categories and which opens up the possibility to think differently, remains to be taken. This thesis offers such an attempt.

# THEORETICAL FRAMEWORK

I mentioned earlier (on page 15) that this project was a piece of nomadic research and that as such, methodologically, it attempts to provide an operationalisation of nomadism as conceptualised by Deleuze and Guattari (1980) and later Fox (1999). This section introduces these terms in more detail and explains their relevance to quality of life.

I do not take a nihilistic stance in this work, but one that acknowledges the constructive power of language and sees it as related to social relations and institutionalised practices. Language, as the unavoidable mediator between an object and its description, but also as something profoundly unstable, marks the broadest challenge to the validity of a rational knowledge of the world (Burr 2003). The concept of power is at the heart of this approach, conceptualised by Fox (1999) as: “an ethical and political project, concerned with engagement with the world, on the side of resistance, and celebrating rather than bemoaning difference and otherness” (1999: ix). It is this stance of postmodernism that will enable me to look beyond quality of life as it is worded in policy documentation and conceptualised by some of its users and providers. This framework will also enable me to study how these framings might relate to wider cultural representations.

Postmodern theoretical perspectives reject the deeply ingrained assumptions of the Enlightenment rationality, or any other supposedly ‘secure’ representation of reality. Postmodern theory was born within the democratic left of French politics in the 1960s and from a general mistrust of political orthodoxies (Agger 1994). Lyotard (1984) identified the postmodern condition with the decline of the authority of ‘grand narratives’, or all-encompassing and totalising accounts that provide comprehensive explanations about the world. Postmodernists devalue these absolute standards, which are seen as oppressive or exhausted. So postmodernism was born out of a dispute of the very ontological status of meaning, which was seen as an ideologically generated illusion (Ward 2003). Postmodernists, by favouring a view in which



reality is socially constructed, annihilated the reigning conviction that knowledge is knowledge only if it reflects the world as it 'really' exists (Kincheloe and McLaren 1994). From this perspective, texts are not facts, only interpretations that are fragmented, discontinued and in conflict with one another.

The postmodern themes of the collapse of grand narratives and loss of trust in expert systems can help to explain the growing challenges to expert discourses. Lay knowledge challenges the 'objectivity' of scientific knowledge, contesting its impartiality vis-à-vis other discourses. According to Williams and Popay (1994):

Lay knowledge, in being open to variation, difference and local significance, has always been postmodern. The vogue of postmodernism ... provides a neat legitimation for lay resistance to expert systems of knowledge ... Lay knowledge about health and illness thus provides an epistemological challenge to medicine. It offers a view of illness that is subjective and often highly coherent... However, in so far as such knowledge about illness remains private, expressed only in the clinic, the home or in casual encounters with others, it offers no direct political challenge to the power of medicine (1994: 123).

A parallel can be drawn here with people's knowledge about their own quality of life, in that as long as it remains private, or only assessed by tools developed by professionals for the use of professionals, it does not challenge the medical power base. Instead of "being open to variation, difference and local significance" (Williams and Popay 1994: 123), quality of life has become an object of study for clinicians and researchers. In that process, its particularities are often denied or ignored. Quality of life should provide an epistemological challenge to the medical profession, but is in the process of being turned into a mere measure of effectiveness. A postmodern approach to the study of quality of life is therefore needed, if one is to shake the assumptions that allow professional power to enter and systematise an individual's private life and, in doing so, silence his or her voice.

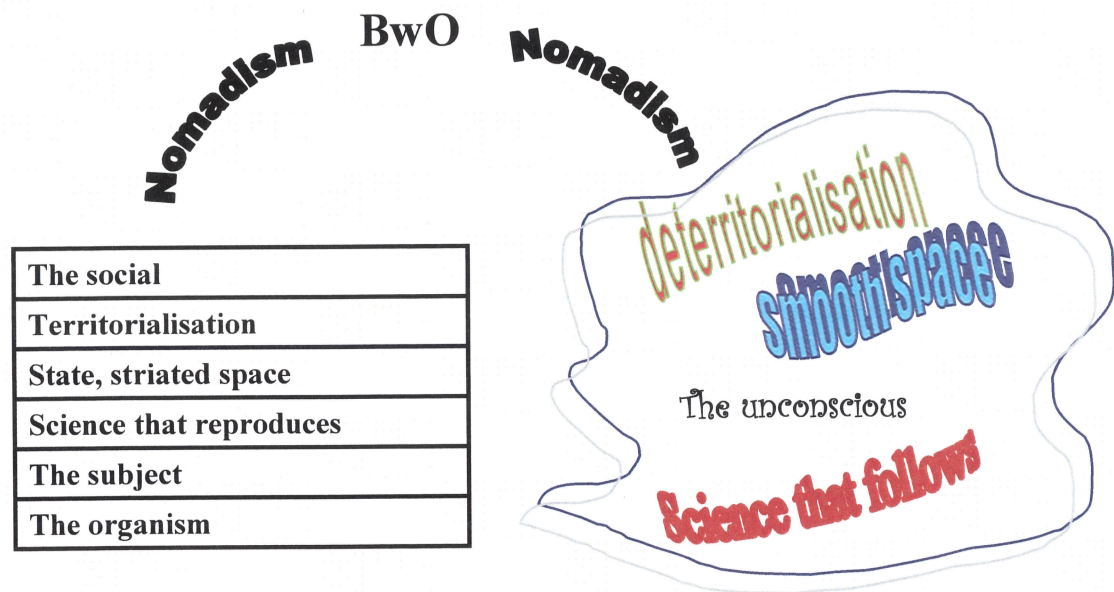
Epistemologically, the body is apprehended differently by modernists and postmodernists. Postmodernists view the body as discursively produced (Turner 1992). That is to say that the body is as the power of medicine, for example, defines it: it exists solely in terms of physiology or pathology, of health or disease. It is perceived through a modernist, dualist and reductionally mechanistic model of

thought. This emphasis put on discursive practices allows for the analysis of how power is mediated in the 'expert' discourses and the effect on the body of the inscription of 'health' and 'illness' categories (Fox 1993). Medicine is therefore seen as a text or a discourse that bears little relationship to the professional groups using it. Foucault (1977) suggested that the basis for medical dominance rests in the knowledge claims of the medical profession about 'the body', 'health' and 'illness'. As such, medicine offers knowledge and techniques, which grant it the power to diagnose and treat bodies (Corker and Shakespeare 2002).

### **The Body without Organs, territorialisation and nomadism**

In 1972 the French philosopher Gilles Deleuze and the psychoanalyst Felix Guattari collaborated on a book called *Anti-Oedipus: Capitalism and Schizophrenia* (Deleuze and Guattari 1972). They feature a world of fragmentation and flux, and advocate for the liberation of individuals from the notion of a single, stable and rational self, which is seen as repressive. They take one step further in the project of decentralising the self and introduce the notions of the Body-without-Organs (BwO); of the territorialisation of this entity by society; and of nomadology as resistance to territorialisation. It is important here to note that being French myself, I have the privilege of being able to read Deleuze and Guattari's work in its original version. What follows is therefore my understanding and occasionally my translation, of their ideas. I will begin with a diagram, to which the reader may want to refer, while reading the following paragraphs.

Figure 1: The Body without Organs



The ‘Body-without-Organs’ (BwO - Deleuze and Guattari 1972, 1980) is a philosophical surface on which social forces act and interact. It is developed within an anti-essentialist framework, in which the self is not an essence that exists independently from external forces. As I understand it, the BwO is a surface that enables an interaction, or dialogue, between our unconscious and the social context in which we live. The BwO is not the physical body: “The BwO opposes itself not to the organs, but to this organisation of organs called organism” (Deleuze and Guattari 1980: 196). The Body is ‘without organs’, because organs are physiological constructs that are *organised* to form our body. This process of organisation entails many classifications, measurements, examinations and external powers to be exercised; the very powers we ought to resist. The body as an organ-ised entity is a dimension of the BwO. The latter is a metaphysical surface which links our unconscious experiences to the forces of society (Deleuze and Guattari 1972). These include the body as an organ-ised entity and the subjectified self. The BwO is born out of the rejection of psychoanalytical efforts to define and reduce subjectivities to phantasms, or to root them solely in the Freudian triade mother-child-father. It is a surface which is characterised by flows of intensity, sensations and feelings. It is not

a concept, but rather a practice that enables experimentation and recognises that our unconscious is constantly re-written through our experiences in the world. The BwO is in a constant state of becoming. Deleuze and Guattari oppose the idea that our unconscious is somehow at the core of our personality. Instead, there is no distinction between the centre and the margins and there is a free-flow of relationships and influences, interweavings and cross-fertilisations that are being permitted by the BwO.

The BwO can be controlled and dominated, as represented by the left hand side of Figure 1, but it is also an experimenting and resisting force, represented on the right hand side. Domination takes the shape of 'striations', to which Deleuze and Guattari oppose the power of 'nomadism' (1980), as the means to get in and out of the state, striated space that is imposed upon us – sometimes by ourselves. The construction of the self is therefore acknowledged to be an ongoing and dynamic, rather than passive, project. This is in opposition with Foucault's ideas, according to which the subject is submissive and pliable entity, on which societal knowledge and power forces are exerted (Fox 1999). The BwO enables a dialectical process to take place between striating societal forces and the liberating possibilities of experimentation as human beings engage with the world.

Between a BwO and what happens to it, there is a very particular relationship... Of analysis... a constant analysis where what happens to the BwO is already part of its making, it is already part of it, on it, as the result of a multitude of passages, divisions and sub-products (Deleuze and Guattari, 1980: 189).

Thus, we can recognise the impact of the social on how we see our body, our life and ourselves. The way people describe their life is the result of "a multitude of passages, divisions and sub-products" of their experiences in the world and of the making of their BwO. So the BwO is pivotal in the relation between the unconscious, subjectivity as one striation and the social environment as an essentially striating medium.

Deleuze and Guattari further describe three concepts that restrain us most directly:

The organism, interpretation (the subject) and the object: You will be organised, you will be an organism, you will articulate your body – otherwise you will be decadent... You will interpret and be

interpreted, be object and subject – if not you will be a mutant. You will be subject, fixed as such.... If not, you will be homeless (Deleuze and Guattari, 1980: 197).

The BwO is a tool we can use to oppose these ruling and defining concepts by disarticulation, experimentation and nomadism. The BwO does not annihilate its own making, since it constantly oscillates between the ruling, organising concepts and its own liberation. Deleuze and Guattari exhort us to experiment and liberate ourselves from our chains, but not in a destructive manner. We should gain awareness of the ruling forces of territorialisation, so that the BwO can experiment and explore, gently extending the boundaries. This is what they refer to as deterritorialisation. Territorialisation is the process by which both society and theory attempt to tame human desire (Ward 2003). For example, in medicine, giving somebody a diagnostic is to territorialise it as that of a 'patient' or as a 'user' of the health care system. To deterritorialise oneself in reaction to this is to see oneself as other, as different from that territory imposed upon us. However, every deterritorialisation ends up being a re-territorialisation. For example, I may be described as an MS patient in a medical discourse and see myself as such during a stay in hospital, but I may favour myself as a parent, or professional person, or whatever else, as soon as I depart from the medical premises. To stop thinking of myself as a 'person with multiple sclerosis' may be a deterritorialisation if I have just gained awareness of the ruling forces that territorialise me as a patient. To start thinking about myself as 'something else' is a re-territorialisation. It is during that split second where I am neither one nor the other that, Deleuze and Guattari argue, I am a nomad. Deterritorialisation is therefore an event that is enabled by the existence of the BwO. However, deterritorialisation is also a project, a way of being, a constant process of becoming.

Sometimes, the BwO moves only a little from a previous position before settling in a new striation. This produces transitory and possibly inconsequential deterritorialisations (Fox 1999). At other times, deterritorialisations can be life-changing, enabling us to see possibilities previously unimaginable and become other. The more developed the BwO, the more we are able to deterritorialise our selves. Deleuze and Guattari (1980) thus distinguish between relative and absolute deterritorialisations. However, an absolute deterritorialisation assumes and builds on

the existence of relative deterritorialisations and vice versa. These movements are part of the dynamics of existence itself. In a nomadic or smooth space, one becomes aware of the forces imposed by society and starts resisting them. This is where I can escape the 'striated' space, which creates me as *either* something *or* something else. The space of nomad thought is qualitatively different from what Deleuze and Guattari name 'State' space. Movement in State is striated, or griddled: it is limited to preset paths between fixed and identifiable points. Nomad space is 'smooth', or open-ended. One can rise up at any point and move to any other. *Capitalism and Schizophrenia* (Deleuze and Guattari 1972, 1980) is an effort to construct a smooth space of thought. Deleuze and Guattari (1980) oppose the smooth space, in which space is occupied but not counted (figure 1, left-hand side), to a striated space, in which space is counted to be occupied (figure 1, right-hand side).

However, it is not only individuals who are the subject of striations. So too are concepts, which need to be deterritorialised so that understanding may be advanced. Quality of life, instead of being the smooth, anarchical and individual space of life itself, has become, within academia and policy, a striated space that *is* because it is *measured*. Science awards it ontological status. It is being transformed in theorisation, rather than simply projected. Nomadic science is very different from State science. To borrow an image from *Capitalism and Schizophrenia*, the State needs to subordinate hydraulic force to pipes and banks that prevent turbulence, and force movement from one point to another, force the space itself into striation and measurement (Deleuze and Guattari 1980). Similarly, quality of life is being subjected to mathematical conceptualisations within academia. It is being forced into theories, framed and domesticated. The hydraulic model of nomadic science involves the turbulent occupation of a smooth space, the production of movement that occupies space and affects it in all its points simultaneously, instead of being kept as a movement from one fixed point to another. In this model, life is a smooth space that is being subjected to the forces of theorisation. Measuring, or quantifying quality of life is to start its striation.

Deleuze and Guattari (1980) also oppose two types of science: that which aims at 'reproducing', and that which 'follows'. Reproduction implies the permanence of a

fixed viewpoint, external to the thing that is being reproduced: watch the river flow, from the banks. To follow is something else; “not better, something else”, Deleuze and Guattari argue (1980: 461). One has to follow when one is after the singularities of an object of study; one has to follow to embrace difference. As exposed earlier, quality of life has been territorialised by history. It is territorialised ontologically, epistemologically and methodologically by social indicator and health researchers, in a model of science that reproduces understandings. Indeed, the ‘reproducing’ science never ceases to reterritorialise from a same viewpoint. Social indicators researchers produce population level indicators of happiness and make this into a political project (see Sirgy et al. 2006 for example). Quality of life researchers in health focus their attention on functional assessments sometimes supplemented by questions on the subjective experience of the disease (Bowling 2001). In the following, or nomadic science, it is the process of de-territorialisation that constitutes and extends the territory. It is a deterritorialisation of quality of life as a concept that I aim to achieve in this work. One that will – ever so gently – extend its current territory. However, as mentioned earlier, deterritorialisation always implies a reterritorialisation on a conceptual map: nomadic sciences invent problems, for which the solution would include collective activities, but the scientific solution depends on the State science. My aim is therefore to identify the conditions of quality of life’s territorialisations and, in doing so, extend the boundaries of our understandings.

## **Deconstruction**

For postmodernists, the way to shatter the illusion that things have a single, basic meaning is to focus on language. This marks a turn to the *text*, and to the examination of social sciences as a matter of writing and of writing in language, which is steeped in ideology. This demands an intensely reflexive approach to the text, towards a disruption, rather than an attempted capture, of meaning (Hughes and Sharrock 1997). A text however, does not have to be written, as it is any kind of “meaningful symbolic system” (Fox 1999: 27) and can therefore be a film, a policy

document, a philosophy or any other set of social practices or culturally produced objects.

“Deconstruction *is* deterritorialisation” (Fox 1999: 135 emphasis in the original text) and, as such, is a tool for resistance to dominant social forces. Derrida (1976) developed deconstruction to highlight and investigate power in the social world, which is conceptualised as textually assembled. Deconstruction does not see the structure of a text as having any objective reality. It begins by suspending the assumed correspondence between meaning and mind, and opposes any ‘method’ that claims to unveil the structure and meaning of a text (Norris 2002).

From a deconstructive perspective, philosophy is strictly a matter of placing some orderly construction, or territorialisation, or striation, upon the immediately perceptible world (Norris 2002). Derrida (1976) refuses to grant philosophy the kind of privileged status it has always claimed as the sovereign dispenser of reason. He advocates a critical reading which unpicks the elements of metaphor and other devices at work in the texts examined. Derrida also rejects the assumptions and practices of science, arguing that they seek to solve intellectual problems with sheer technique, thus falsely achieving a ‘truth’, which is then organised in ideologically steeped language.

Derrida repeatedly warned that his texts are not a store of ready-made ‘concepts’, methods or methodologies, but an *activity* resistant to any such reductive ploy (Collins and Mayblin 1996). Fox (1999) describes deconstruction as “a perspective, a mood... a political position committed to the side of resistance, transformation and regeneration” (1999: 27). Derrida’s line of attack is to unpick loaded metaphors and show how they work to support a whole structure of presuppositions. Therefore, the term ‘deconstruction’ is highly resistant to a succinct, formal definition, in the context of Western metaphysics. Some have attempted to explain what deconstruction is *not*. It is not a synonym of destruction, but rather:

[deconstruction] is in fact much closer to the original meaning of the word ‘analysis’ itself, which etymologically means “to undo” – a virtual synonym of to de-construct. If anything is destroyed in a



deconstructive reading, it is not the text, but the claim to unequivocal domination of one mode of signifying over another (Johnson 1980: 5).

Deconstruction is neither synonym of nihilism or extreme relativism, as it seeks to reveal the hidden assumptions of systems in order to open public debate about them. Far from refusing values, Derrida wants to open up dialogues about them, albeit in a humble manner that recognises the impossibility of achieving any kind of foundation, or truth (Agger 1994).

For Derrida, the smooth surface of a text is an illusion created by the attempted suppression of internal contradictions. Deconstruction aims to dismantle this illusion. It highlights themes, ideas and values that the text tries to deny or ignore as irrelevant. A text always exists through an 'other', which it presents as 'exterior' to itself. This means that it depends, for its 'identity', on its construction of an 'outside'. The outside and the inside cannot, therefore, exist independently of one another, so the margins between them are unstable (Ward 2003). So Derrida is interested in borders and questions what is inside and outside of the 'proper' boundaries of the text. Derrida's texts are therefore not located 'outside' of the texts they examine in a supposed position of privileged authority. Rather, they inhabit them and make a destabilising passage through them by revealing and undoing their assumptions (Collins and Mayblin 1996).

Crucial to deconstructive approaches are the notions of text, or intertextuality, and frame. Intertextuality is the process by which a text recalls, or refers to, other texts (Barthes 1977). In as much as a text territorialises its subject matter, intertextuality is a kind of inter-territorialisation. All texts are intertextual, in that they inevitably draw from a vast repertoire of codes, conventions and influences. So a text exists inescapably in relation to a vast array of other texts, mostly by other authors. No text exists in a vacuum or speaks its own tongue. The references cited in this thesis are intertextual links to other people's work, which make reference to yet other texts, and so on. Thus, intertextuality is not so much a matter of style as a structural property, which allows texts to be produced and readers to read them. A text only gathers meaning because it is, as Barthes states, "a tissue of quotations drawn from the innumerable centres of culture" (1977: 146). It is both inscribed with the traces of

the texts that have gone before it, and formed in the act of reading by all the references we all carry with us. It derives from this, therefore, that it would be mistaken to consider a text, concept, or a person, as subjected to one territorialisation at a time. We are all subject to multiple territorialisations at any one time: the patient does not cease to be a mother or a worker or a music fanatic while she is in hospital. This is similarly the case with concepts: quality of life is neither a social statistic or linked to a subjective sense of self. It is both, dependant on the contextual territorialisation considered. Either, or both, may be prevalent at any one time.

After viewing *The Notebook*, I felt that death was portrayed as the one place where the two main characters could be reunited as man and wife. So death was a return to some form of social norm of marriage, since once dead, they could be together for eternity. Or, in other words, death with all its uncertainties was preferable than life with dementia. The film is very emotional, because it appeals to shared normative ideas: it is based on the modernist utopia of a healthy and eternal life. Pushed at the periphery of the film is the sense of grieving for the lost life that they try to regain through the reading of their life story. The emphasis could have been placed on the time they were spending together as friends, sharing peaceful moments while reading a beautiful love story. Instead, the accent was put on their lost 'normal' life. This relates to ethical debates about what a normal life may be, and the quality of life of people living with sensory or physical impairments. This is how I, as a territorialised subject, with my frames, feelings, ideas and references, perceived this film. For every reader, or in this case, viewer, every such text is webbed into a series of related texts. Highlighting a chain of reference between them helps to apprehend the meanings conveyed in a more open-ended way. A text is thus the site of territorialisations and to look at its intertextual links is to attempt a deterritorialisation.

Focusing on intertextuality can thus contribute to a questioning of the limits of a system of thought, and thus to open up the possibilities of thinking differently (Bogue 1989; Curt 1994; White 1991). It contributes to breaking down the strict dichotomy between researchers and research subjects, as the researcher becomes overtly and explicitly part of the text that she explores and describes (Fox 1999). In

reporting my research, I become part of an intertextuality such that I can no longer stand apart from the research setting. This is the reason why, in the introductory chapter, I wrote episodes of my life that I feel had a significant impact on the person I am today. While I write this project, it does not stand apart from me, and what I bring to it becomes crucial to what it is; my life so far is therefore a text woven into this piece of research.

Another notion crucial to deconstruction is that of the *frame*. The frame, or boundary, of a text is where it collides with other texts; it is what distinguishes what it is from what it is not. If a text is seen as the territorialisation of its subject matter, it follows that the frame is the border of this territory. The frame is therefore an intrinsic, if not explicit, characteristic of a text. However, it does more than enabling sense making for a concept or an individual, since subjectivity itself is a framed text. Thus, subjectivity is seen as a dynamic process of reframing as one engages in intertextuality, in a continuous process of becoming (Fox 1999).

In this work, long-term conditions are used as a frame to study quality of life. Within the text of long-term conditions, quality of life is territorialised in ways which I will explore in this thesis. Derrida (1987) sees the frame as what gives meaning to a text: words only mean something in relation to other words and the same goes with texts; their meaning is not intrinsic. In other words, quality of life in health care does not have an intrinsic meaning, but rather means in relation to notions of health, illness and the body. The frame is also the place in which power acts. It derives from this that the right to speak the truth in relation to long-term conditions derives from their delimitation on a conceptual map. To use long-term conditions as a frame to support deconstruction is to question the power base that defines quality of life in relation to a bodily status. This questioning does not want itself to be negative or condemning of existing conceptualisations. Rather, it constitutes a deterritorialisation, in that it considers quality of life not as something given or static that science is striving to uncover, but as something from which positive change can emerge.

A number of implications derive from these Derridean readings. Firstly, while individuals write texts, the meaning ascribed to them by a particular reader is always temporally and spatially contingent. Authorship is therefore provisional. While the authorship of this work is mine while *I* am *physically* writing it, as soon as another reads it, the authorship escapes me and becomes theirs. Secondly, intertextuality contributes to subjectivity as much as it does to knowledge or ideology. This thesis is a journey, a philosophical, personal journey. As I read and produce texts, they all contribute to the making of my own subjectivity. Deleuze and Guattari (1972, 1980) describe this as a ‘nomadic subjectivity’ which is at once drawn to instability and travel, and attracted by one framing or another (Fox 1999). This does not imply that such intertextual, or nomadic, subjectivities are free in any absolute sense. In reality, texts compete to deny alternative readings, constraining potential nomadic practices. Biomedicine is an example of such a frame. Identifying these competing texts and the framings involved in people’s quality of life evaluations and official documentation will be crucial to this work. Ultimately, in doing so, I aspire to create a smooth, or smoother, intertextual space in which to look at quality of life.

# Nomadic research in practice

Methods texts can be seen as science's equivalent to a religion's holy book: setting out the right way to do things, and the 'threats to validity' which come from not following the prescriptions... (Fox 1999: 175).

The word 'method' refers to an orderliness of thought that is steeped in modernist scientific discourse and sets the way to reach a reliable truth. It is therefore deeply at odds with what I am trying to achieve here. Postmodern research opposes the idea that truth is out there, waiting to be discovered with the right methodological tools. That does not mean that one cannot 'know' about things, but rather, that a number of truths can concomitantly exist, which are inevitably temporally and spatially contingent. This view embraces diversity, complexity and difference, rather than seeking to differentiate, classify and define (Haber 1994). Adapting an analogy used by Fox (1999), the contrast between modern and postmodern systems of thought can be illustrated by the difference between a scientist and a nomad. The scientist, as an icon of modernism, describes, names and organises the world in its minute details, in a hierarchically understandable way. In Deleuze and Guattari's (1980) words, he or she produces a 'striation' of the world. By contrast, the postmodern nomad does not attempt to dominate his environment. He inhabits a smooth space, where things are perceived rather than named. He embraces difference not by, like the scientist, differentiating, organising or opposing, but by accepting each and every aspect of the environment as unique and equally important. Therefore, the texts I chose to study do not mean to delineate some version of quality of life. They are a necessary and, by nature, restrictive step to painting some representation of quality of life, but also aim to show just how vast and multifaceted the concept is. If this thesis was a painting, these texts would act as indicative of particular characters or elements of the landscape, rather than as truthful restorations of every nook and cranny of the quality of life field.

In a postmodern framework, 'method' is merely a text, which aims to convince the reader of the validity and veracity of the subsequent analysis, and which requires deconstruction in favour of a more self-reflective version of itself. Since the aim of this thesis is not to convince the reader of the truthful status of any claim I may make by the end of this document, then the need for a step by step method of analysis becomes redundant. Nor do I conduct this analysis so that it may be replicated or applied to other fields. A method, it may be argued, also ensures that the work was conducted rigorously. Yet rigour itself is a text in need of deconstruction. While I have read each of the texts included here at least three or four times, this does not ensure rigour in itself. Rigour is rather ensured through the relevance of my analysis to both the quality of life field and the reader. I found some texts more demanding than others, as they required repeated readings in order that I could absorb, understand and unpick what lied inside and outside of each of them. Rigour will therefore be ensured if my analysis engages the reader and permits assumptions to be questioned and boundaries to be extended. This may be different for every single reading. Hence what follows is not a 'method' chapter as such, but rather a text that sets the scene, or the mood, in which the analysis will be conducted.

So far in this thesis, I have first introduced different approaches to quality of life and then postmodernism, which considers them as texts in need of deconstruction. Long-term conditions are used as a frame through which quality of life is looked at. So in this work, texts related to long-term conditions constitute physical supports to a deconstructive approach to quality of life, and the reader is taken through a journey of deconstruction through which she may assume some authorship. Fox (1999) recommends that postmodern research should at least reject the dualities of researcher / research participant; research / experience and theory / practice and in this, deconstruct the foundations of modernist research. A modernist research project often presupposes a linear process of understanding, where a question is asked and then answered. As exposed earlier, in this project the research question has evolved and the end product aims more to disrupt the meanings associated with quality of life in long-term conditions, rather than to create new truths. Fox further asserts that "methodological pluralism or eclecticism" (1999: 191) may be key in postmodern

research. Contrary to a modernist piece of research, the 'subjects' of my research are not people, but texts. Some were produced through interviews, but others are cultural texts and policy documentation. The texts I have chosen limit what can be said and my analysis of them is necessarily limited in itself. While this section does not describe a method, what follows is not a result section, but rather a textual journey through which I wish the reader to assume authorship of her own reading and interpretations. The way in which I achieve this is through the presentation and ordering of chapters in the next section, rather than in their particular contents. In doing this, I implicitly extend the frame within which concepts such as 'method', 'result', 'analysis' and 'data' are generally understood in a conventional thesis. My analysis is therefore multilayered, as it situates itself both within the texts it deconstructs and with-out them, in the context of the textual journey.

In providing deconstructive readings of both individual life stories and national policy documentation, my hope is to extend the boundaries of our current understandings of quality of life. The inclusion of cultural artefacts acknowledges and situates both participants' words and policy documentation within the cultural context of contemporary Britain. The multiplicity of these data sources will in itself provide a smoother space for an exploration that intends to celebrate difference and otherness while resisting striation. The ordering of the analytical chapters is in itself part of the method; I will go back to this at the beginning of the journey, on page 77. In reference to the concept of the death of the author (Barthes 1977), which engages readers in authorship, chapters are placed in a dis-organised multitextual journey that aims to create a smooth space. The intention is for the reader to form her own conceptualisation of quality of life in long-term condition, in the course of this disruptive journey.

## **The texts**

The texts studied as part of this analysis include health service users and developers' experiences, a sample of policy documentation and media texts:

- a) Qualitative data extracted from an evaluation of three service developments for people with MS. This includes interview and focus group data with service users, service developers and field notes;
- b) The National Service Framework for Long Term Conditions;
- c) A sample of popular television programmes and a Disney Classic production.

### **a. Service Evaluations**

In line with national and international policies (WHO 2002; DoH 2001a, 2001b, 2002), in 2002 the MS Society funded three service developments for people with MS in the North of England and their evaluation (Dawson et al. 2004). The models of service delivery, their intervention components and the characteristics of the people using the service were all considered for the evaluation. The research team collected a range of anonymised demographic and MS related data through each of the service developers, in order to describe their service. As part of the research team, I conducted qualitative interviews of service users, carers and service providers, in order to explore their experiences in relation to the service. I also kept field notes. Interviews included the use of the SEIQoL, which served as an anchor for discussions around quality of life. It is this qualitative strand of the evaluation that I will use in this thesis.

### ***The Schedule for the Evaluation of Individual Quality of Life***

I used the Schedule for the Evaluation of Individual Quality of Life – Direct Weighing (SEIQoL-DW) to measure quality of life in this project, because it recognises the individuality of the person and their existence beyond a certain diagnostic group (O'Boyle et al. 1995). It is administered in the form of a semi-structured interview in three phases:



1. Cues elicitation: The respondent names the five areas of life (cues), which are of greatest importance to his / her overall quality of life.
2. Cues levels: The respondent rates current status against a vertical visual analogue scale ranging from 'as good as could possibly be' (0) to 'as bad as could possibly be' (100).
3. Cues weights: A disc weighing system is used, which consists of five interlocking circular discs of different colours on a base scale over 100. Each disc is labelled with one of the respondent's life area. The discs may be rotated independently over each other. On completion, one is left with a circle composed of different coloured segments each representing the weight given to a particular area of life.

Each cue level can be multiplied by the corresponding cue weight and divided by 100. The products are then summed across the five cues to give a global SEIQoL score. This score can range from 0 to 100, with higher scores indicating better quality of life.

### ***Semi-structured qualitative interviews***

Interviews with service users and providers were semi-structured, but whilst an interview schedule was used, the interviews were set on a conversational, non-directive mode, which enabled people to express opinions beyond the strict frame of the research. People came to the interview with their self-interpretations and pre-understandings. The transcripts analysed in the subsequent chapters are therefore the results of that shared moment in time between the participants and me. The words used were used as a result of that unique moment in time, between two persons with distinct and unique personality traits. In order to pre-empt interviewees from making assumptions about my standpoint and therefore hopefully facilitate the exchange, I informed people from the onset that I did not have a medical background and knew very little about MS, other than what other people with MS had told me. In doing this, I was hoping to set the scene for a lay discussion around service use and the experience of having MS and hoped to dissolve some of the interviewer / interviewee or academic / lay person power relationship that might have influenced their comments. The same principles were used for one focus group, which was organised at one of the sites evaluated (service A).

Each service had particular aims, target population and environment, which are described below.

### ***Service A***

Service A was established following a needs assessment survey of rehabilitation services for adults with a neurological condition in the area (Crawford and Bearn 2000), which constitutes one of the most geographically isolated communities in England. The aim of the project was to improve and develop the service offered to MS patients in the area, by providing some dedicated MS physiotherapy time. The post allowed specific groups to be reached by physiotherapy services from which, for geographical or logistical reasons, they would have been excluded prior to that. The geographical area covered by the post was 685 square miles, where an estimated 180 people with MS lived. The post-holder was in a position to offer a flexible service, which could be made available to people in their home or out-of-hours. He was also linked to a local Young Disabled Unit, which provided patients with a central point of contact, as well as access to facilities and a multidisciplinary team. Over the two year evaluation period, 47 people were referred to the service. They were between 30 and 72 years old, 61% of them were women, and had on average been diagnosed for 10.7 years. 44% of them scored highly on the Expanded Disability Status Scale (EDSS - Kurtzke 1983), suggesting that a large proportion of these patients were severely impaired.

*Data collected:* During the time scale available for data collection, five new referrals to the service agreed to be interviewed individually, before and after the physiotherapist's intervention. Quality of life was assessed with the SEIQoL. One family member, the physiotherapist and his line manager were also interviewed, and a focus group was conducted with a mixed group of people, including four individuals with MS and two family members.

### ***Service B***

This was a self-management and education programme for people with minimal impairment. Its aim was to improve exercise tolerance and prevent deconditioning and possible secondary complications. It gave access to support, advice and

professional information. The proposal to the MS Society was based on the development of the MS Society 'Standard of care for people with MS' (MSS 2002). For many years, patients with MS have been advised to avoid exercise because of excessive fatigue and thermosensitivity. However, several recent studies have indicated positive improvements on a range of responses, including increased muscle strength and improvement in physical function, depression and fatigue (Petajan and White 1999; Freeman 2001). The programme was running over a period of 14 weeks, combining informal information sessions and supervised gentle exercise. The physiotherapist leading the initiative developed the acronym ACTIVE, which stood for Advice, Coping mechanisms, Training, Information, Value your health and Exercise.

The 14-week programme comprised combined information and exercise sessions held over a 3 hour period, once a week, for 6 weeks. Exercise was continued in a leisure centre under the instruction of a Health and Fitness Adviser for a further 8 weeks. Two groups of patients went through the programme over the two year evaluation period. All but one participant, who had a relapse, could take part in the evaluation. They were between 20 and 60 years old, 72% of them were women, and they all presented with minimal impairment according to the EDSS. Their mean time since diagnosis was 3.9 years.

*Data collected:* 14 people with MS were interviewed immediately before and after the intervention, and their quality of life assessed with the SEIQoL. The lead physiotherapist, her line manager, the health and fitness adviser and the local MS nurse were also interviewed.

### ***Service C***

An MS relapse clinic was set up (Craig 2002) following a research project that evaluated the benefits of focused multidisciplinary management, combined with intravenous steroids for relapse (Craig et al. 2003). The results indicated clear benefits to the patients and spurred the research physiotherapist to set up a weekly relapse clinic combining these two components. The multidisciplinary team consisted of a consultant neurologist, a registrar, an MS nurse specialist, an

occupational therapist, a physiotherapist and an orthoptist. This clinic allowed all patients experiencing a relapse to be fully assessed by a multi-disciplinary team in a single visit to the hospital. This contrasted with previous relapse management, where people would have to see the consultant first and then other professionals, according to identified needs. In this new relapse clinic, all professionals had an input in deciding, in collaboration with the patient, where, when and how the relapse should be treated. The format allowed patients to be seen more rapidly after their relapse and all complaints to be addressed in one visit that was then followed up by the relevant professional(s) according to identified needs. A follow up consultation with the team was organised approximately six weeks after the initial visit. The data for 23 patients was collected during the evaluation. They were between 23 and 68 years old, 20 of them were women and their mean time since diagnosis was 10.6 years (range 2-25 years). The patients presenting to the clinic all had minimal to moderate impairment according to the EDSS.

*Data collected:* Due to the nature of the service and the unpredictability of the relapse episodes, retrospective interviews were conducted. 10 people were selected using a sampling matrix developed with the service co-ordinator to reflect the diversity of the population served. Potential participants' details were communicated to the research team at their review visit, 6 weeks after their relapse. They were interviewed within a fortnight after that. Five professionals, all members of the multidisciplinary team, were also interviewed.

#### **b. NHS policy documentation**

I use the NSF for long-term conditions as an exemplar of current political thought on the needs of people with long-term conditions and the ways in which services should respond to those. It is the most recent policy document that focuses on neurological conditions, with recommendations said to apply to all long-term conditions. As described earlier (page 33), this is the first NSF for which such an emphasis is put on user perspectives and as such, it is particularly suited to the present analysis. At the core of this NSF are eleven Quality Requirements (QRs) for services:

- QR1: A person - centred service
- QR2: Early recognition, prompt diagnosis and treatment
- QR3: Emergency and acute management
- QR4: Early and specialist rehabilitation
- QR5: Community rehabilitation and support
- QR6: Vocational rehabilitation
- QR7: Providing equipment and accommodation
- QR8: Providing personal care and support
- QR9: Palliative care
- QR10: Supporting family and carers
- QR11: Caring for people with neurological conditions in hospital or other health care settings.

The document as a whole is subjected to a deconstructive analysis in which the notion of the care plan, as well as what is meant by independence, quality of life, health, patient centredness and empowerment, as well as time and space, are explored.

### **c. Cultural artefacts**

#### ***Popular television***

##### **Rationale**

Cultural representations set the frame and therefore the boundaries, around what is considered normal (Barnes et al. 1999). The aim of this analysis is to explore how health and disease are currently being presented in popular television. Gross (2001) asserts:

representation in the mediated reality of our mass culture is in itself power; certainly it is the case that non-representation maintains the powerless status of groups that do not possess significant material or political power bases (2001: 406).

If people with disabilities have gained ground in media representation over the past decade (for example as fashion icons, see Kupperts 2002), my assumption in conducting this analysis was that this may not be the case for people with long-term

conditions. However, if they were represented, I needed to know how this was done and what the assumptions underlying this representation could be, as well as the discursive practices supporting it. Non-representation as well as representation would have significant implications for my analysis of the conditions of representation of quality of life in enduring health needs.

### The data

The data informing this strand was collected from the 1<sup>st</sup> to the 31<sup>st</sup> July 2005. For four weeks, I watched every health related programme on mainstream television (BBC1, BBC2, ITV, Channel 4, Five), starting between 19:00 and 23:00 every night. Cumberbatch and Negrine (1992), in their content analysis of the representations of disability on television, used a broader sampling frame, since they conducted a content analysis of all peak time television programmes, over 6 weeks in the summer and autumn of 1988. While Cumberbatch and Negrine's (1992) analysis was comprehensive enough to form the material of a book, the point here is to provide a support to the cultural backdrop of our understanding of quality of life in long-term conditions. Over the summer, television programmes are often repeated and I was hoping to capture some background broadcasting about health rather than the more novel and sensationalist programmes kept for September. The timing of the programmes included was chosen as that with the highest potential viewership.

I did not include serial dramas in this analysis, because although they may punctually figure some characters with long-term conditions, they are not explicitly about health and are therefore at odds with my sampling frame. Wilde (2005) has recently completed a study of the representation of disability in 'soap operas' and concluded that their representation of disability was within a moralistic and normalising framework at odds with the experiences of disabled viewers. This is an important finding that is likely to be of relevance to all viewers with long-term conditions, who may, on occasions, experience disability. She also highlights how disability tends to be related to cause-and-effect plots which strongly associate bad morality with illness (Wilde 2005). Wilde not only looked at the content of episodes, but also interviewed disabled and non disabled viewers to elicit their reactions to them. Such a

comprehensive analysis would not have been augmented by the inclusion of serial dramas in my data strand.

A relevance or purposive sampling method (Krippendorff 2004) was applied, in that all textual units, or programmes, which could contribute to answering the question were included within the time period established. The frame of long-term conditions used for the rest of the thesis could not be applied, since very few programmes are specifically about them. The programmes included were therefore explicitly and more inclusively related to health, disease or the health care system.

Stokes (2003) describes in detail the stages of content analysis. The first one is the statement of the hypothesis to be verified; in this case that long-term conditions are not represented in health related television programmes. She recommends that three half hour episodes of a television programme might be enough for a detailed content analysis. My focus however is not so much to know what particular programmes may be about, but to find out more broadly about the representations of long-term conditions. I therefore chose the time lapse of one month, so as to minimise the impact of single programmes. This would provide three to four episodes of each repeated programme, as well as increasing the chances of capturing one-off documentaries, for example.

529 programmes were broadcast over the month in the time period included. The choice of the programmes included was rather inclusive, but inevitably arbitrary. For example, a series called 'Secret of the Sexes' was broadcast (BBC1), which explored the behavioural, societal, cultural and physiological differences between men and women. One episode of the series concentrated on neuro-physiological differences. At first I included it and then, dismissed it. Such arbitrary decisions, which inevitably relate to my definition of health, had to be made throughout the month. I was looking for representations of the lived experience of long-term conditions that could inform our thinking on quality of life, to which such factual and physiological data would not contribute. I came to this TV content analysis with preconceived ideas that have inevitably influenced the programmes included in the study, as well

as the specific words retained as health related, or their subsequent classification for analysis.

### *The Classic Disney feature*

*Pinocchio* was written as a very successful serial story aimed at both adults and children in nineteenth-century Italy. Over the years, it was translated into English and reinterpreted on numerous occasions (Wunderlich and Morrissey 2002), the most famous of those being Walt Disney's version in 1940. As often happens with myth, the puppet hero has permeated popular consciousness, while the particulars of the original myth have been subjected to new interpretations. Byrne and McQuillan (1999) argue that Disney's films "act as a symptomatic concentration of all the ideological contests, which are currently being fought in the world today" (1999: 168). *Pinocchio* (1940) is no exception, and this makes it ideal material to the present study. The participants in the various studies are all likely to be familiar with the film and most readers of this work will also be. Among other Disney features, it has become a cultural icon that has bearings on our conceptions and assumptions about the world.

The data for this strand consists of the transcript from Disney's *Pinocchio*. The analysis focuses on the making of both Collodi's and Disney's *Pinocchios* and describes the historical and cultural contexts of their making, as well as their implication and significance on the ways in which life with a long-term condition is perceived. This work aims to be sensitive to the filmic experience of the feature-length animation, which is ultimately irreducible in Disney. While for obvious reasons it would be difficult for me to reproduce any of the images discussed, I hope that detailed descriptions of scenes will suffice for the reader to engage with the analysis. I hope that the visual material under consideration is already familiar enough to the reader, so that a lack of reproduction does not bar understanding, and prove my point about the permeation of the contemporary social fabric by *Pinocchio*.



## Textual analysis

### a. Analysis of written texts

The beginning of this chapter has partially set the deconstructive mood in which I intend to analyse this data. A common strategy used in deconstructive analyses is to look at binary oppositions within a text and to show how, instead of describing a rigid set of categories, the two opposing terms are actually fluid and impossible to fully separate (Collins and Mayblin 1996). A deconstructive approach sees, in all the classic dualities of Western thought, one term as being 'privileged' over the other. The privileged, central term is the one most associated with the phallus and the *logos*. Examples include: speech over writing, presence over absence, identity over difference, fullness over emptiness, meaning over meaninglessness, mastery over submission, life over death. Derrida argues in *Of Grammatology* (1976) that in each case, the first term is classically conceived as original, authentic and superior, while the second is thought of as secondary, derivative, parasitic. These binary oppositions and others of their form must be, he argues, deconstructed. The deconstruction of a binary opposition is therefore not a negation of difference, but "it is an attempt to follow the subtle, powerful effects of differences already at work within the illusion of a binary opposition" (Johnson 1980: xi).

In the case of this study, I conceptualise quality of life in long-term conditions as being underpinned by five oppositional pairs. These are:

- *life and death*, because to talk about quality of life is to assume a clear and fundamental difference between the two concepts;
- *health and disease*, because in the context of health care, people are assumed to have a poorer quality of life when they are ill;
- within this framework, *independence* assumes prominence over *dependence* as the latter is associated with poorer quality of life;
- in a political context that vows to be patient centered, a key to improving people's quality of life is their empowerment to make decisions over their own care and the services they receive (DoH 2002, 2004). This is based on the prominence of *empowerment* over *disempowerment*.

- finally, a crucial element of long-term conditions that is seen as detrimental to people's quality of life is the uncertainty of their illness trajectory (DoH 2005). *Certainty and uncertainty* therefore constitutes the last oppositional pair deconstructed.

This deconstruction of underpinning dualities of quality of life, which involve revealing the hidden assumptions behind these concepts so as to question their foundations, forms a thread through the textual journey. Each deconstruction of a pair both informs and is informed by the other textual analyses. However, this focus on oppositional terms and the questioning of strict dualisms is used as a strategy throughout the analysis.

Derrida, in introducing deconstructive practices, enables us to identify the theories and frames at play, so that conceptually we can see beyond them. Deconstruction pushes into the centre themes, ideas and values that the text tries to push to the periphery. No theory or text is a self-contained, totally coherent system. Derrida questions what is inside and outside of the 'proper' boundaries of the text. Deconstruction demands an intensely reflexive approach, towards a disruption of, rather than an attempted capture of, meaning (Hughes and Sharrock 1997).

Following Fox (1999) and Giddens (1984, ch 3), I consider spatiality and temporality as key in the mediation of power. A focus on spatiality questions the existence of boundaries and puts an emphasis on transient movement. It also highlights the efforts to make space a static and stable quantity and to separate it from time (Thrift 2006), and therefore fits into Deleuze and Guattari's (1980) notion of striation. Thrift (2006) sees space as "the very stuff of life itself" (2006: 145), which, if it can be better appreciated, may "feel like something that is both caring and in need of care" (2006: 145). I examine aspects of newly developed, more 'patient centred' NHS services and experiences of health and care, to expose how space and time may be used as both techniques of power and strategies for resistance. I also explore how these dimensions of space and time might "shape human growth and self-actualisation" (Fox 1999: 76) and through this, might impact on people's quality of life.

As the reader might have gathered, some of the data analysed here has not been collected solely for the purpose of this piece of work. This implies that not all, in the texts at hand, is relevant to the study of quality of life in relation to long-term conditions and that I, as the writer, will be extracting from the texts (transcripts, Disney feature, television artefacts and National Service Framework) paragraphs that I see relevant to this work. This, from the point of view of more traditional research, could be seen as introducing a 'selection bias'. There are two points worth considering here: the first is that 'selection biases' are seen as threats to the 'generalisability', or external validity (Lincoln and Guba 1985), of a data sample. From a postmodern viewpoint, these claims of validity are merely rhetorical, since there is no one 'truth' out there, but a multitude of truths that are context contingent (Richardson and Coulthard 2005). Generalisability is irrelevant, since it only serves to create the very metanarratives that are rejected, or opposed, by postmodernism (see for example Lather 1994, on rhizomatic validity). This research is not about seeking to achieve some degree of external validity, but rather about studying the conditions of the uses of 'quality of life'. The fact that texts will not be analysed in their entirety will not alter the relevance of the findings. The second point is that a 'selection bias' will be introduced by the fact that I, as the writer of this piece of research, will be selecting the extracts that I wish to read deconstructively. There again, this is not an argument that holds in postmodern, nomadic, intertextual research: I as the author am an integral part of this research project, of this text that I am writing and which is at the same time impacting on my subjectivity.

The considerations expressed thus far will lead me to look at the notions of time and space, but also at binary oppositions within the texts. The analysis will lead me to reverse these oppositions whenever possible, but also to look at intertextuality, or the texts within the text, and frame, or the texts outside of the text. However, the reader should not expect these to be applied in a methodical and systematic manner: it is a smooth space that I will attempt to create, one in which each reader will be able to look differently at quality of life.

## **b. Cultural analysis**

### ***Popular television***

A content method of analysis is used with these programmes. I chose this method in order to attempt to elicit the signifiers of long-term conditions in television and then elicit discursive trends. So the point of the analysis is not only to count, but to estimate how, qualitatively, people with long-term conditions may be represented. Cumberbatch and Negrine (1992) undertook a content analysis of television programmes to uncover modes of representation of disabled people. They concluded that disabled people were both mis-represented or represented in a partial way. Disabled people were most frequently linked with storylines of treatment and cure, and some programmes focused on their 'special achievements'. The thrust of these representational practices seems to be that disabled people are represented in simplistic, one-dimensional and stereotypical ways (Barnes et al. 1999). While Cumberbatch and Negrine's (1992) analysis may give us a good idea of what might be found, it is restricted to images of disability, as opposed to those, if they exist, of people who may move in and out of impairments over a number of years. Their analysis also took place over a decade ago and therefore calls to be built on.

The intellectual roots of content analysis can be traced back to the beginning of the conscious use of symbols, such as writing (Krippendorff 2004). However, Krippendorff asserts that content analysis "transcends traditional notions of symbols, contents and intents" (2004: xvii). By this, he means that researchers can no longer limit their focus on symbols or representations and that a redefinition of content analysis is called for; one that aligns content with how contemporary society operates and understands itself through its texts. Texts are analysed and acquire significance in the context of their use:

although data enter a content analysis from the outside, they become texts to the analyst within the context that the analyst has chosen to read them... a context is always someone's construction, the conceptual environment of a text (Krippendorff 2004: 33).

In this work, the context is a thesis looking at the representations of quality of life in long-term conditions. Content analysis, therefore, appears to be the ideal tool to verify my assumption about the lack of representation of long-term conditions in

health related television programmes. Content analysis has been criticised for being one-dimensional and superficial and has, in recent years, been superseded by more multidisciplinary modes of analyses involving deeper textual critique (Darke 1998; Barnes et al. 1999). In this thesis, however, the aim is not to produce results that will stand alone, but rather act as support to the rest of the work, which engages in multilayered analysis.

Stokes (2003) recommends a clear definition of the categories of content to be counted. Given the importance of language and discourse in this work, counting words seems most appropriate. This enables me to elucidate not only the frequency at which long-term conditions are mentioned in the texts included, but also the discourses used in relation to them. Stokes (2003) also recommends that the categories to be counted are defined in advance in order to verify the hypothesis. In slight contrast to that, I first watched health related programmes and counted health related words. This included generic terms, such as ‘health’ or ‘disease’, as well as specific terms, such as ‘irritable bowel syndrome’ for example. I also included references to the health services and health professions, in congruence to the qualitative analysis of the three health service developments included. From these words emerged categories, rather like those emerging from a deductive analysis of qualitative research data. These were:

Care professions or specialties	Body parts, fluids or signs / ‘patient’
Medical conditions or descriptions	Drugs, treatments and side effects
Symptoms	Health promotion
Trauma	Death
Surgery	Life
Health care settings and organisations	Experiential accounts
Investigations and tests	Other
Intervention or procedure	

For each programme, I then developed a data collection sheet for the recording of all health related terms mentioned in the programme.

### ***Disney Feature***

Gardiner (2004) describes a technique that he calls ‘reverse marking’, which is similar in its conceptualisation to deconstruction. It brings to the foreground “the ‘negative space’ that exists at the margins or in the interstices of socially ‘marked’

phenomena” (2004: 230). He describes this methodology as a useful way to problematise the taken-for-granted elements of our worlds and make them more visible. While Disney has famously been analysed and critiqued many times over, things remain to be said about the sociological implications of his oeuvre (Byrne and McQuillan 1999), as features such as *Pinocchio* form part of the taken-for-granted cultural backdrop to Western societies.

Byrne and McQuillan (1999) produced a deconstruction of the Disney oeuvre since the emergence of the ‘New World order’, through a deconstruction of the political culture. While their work is much broader, in terms of the time period, thematic issues and number of features analysed, their deconstructive approach was nevertheless of great influence for the approach to *Pinocchio* related here. Throughout the book, they alternate between reading of individual Disney texts, and wider thematic concerns such as race, gender, sexuality or American contemporary culture. While I focus on a single Disney feature and the broad theme of long-term conditions, I use similar techniques in placing the feature in the historical moment of its making and overturning classical oppositions. In addition to this, I consider the original story and expose how the changes that occurred in its ‘Disneyfication’ are a reflection of the cultural and political times of its making in America and broadcasting in Europe. While this is an analysis in time, in that it relates to the times of the making of the feature, there is also a timelessness in its implications. While contemporary children grow up watching *The Incredibles* (2004), they also no doubt know about Pinocchio’s growing nose, and the conceptual order which enabled the making of the feature in 1940 still remains today. In being ‘out-of-date’, *Pinocchio* immediately has no date; it is with-out a date and therefore as current as ever.

## A (rhizomatic) textual journey

Deleuze and Guattari introduce the idea of a rhizome, as opposed to principles of organisation and striation, to explain the non-structure of *Mille Plateaux* (1980). The rhizome connects any point to another point and each of its strands does not necessarily lead to a strand of the same nature. It is not made of unities, but rather of dimensions. It has no beginning or end, but rather a centre, from which it grows. *Mille Plateaux* is therefore made of plateaux, rather than chapters, which can be read in any order and the reader may see links between any few plateaux, in any temporal and spatial order. It is this rhizomatic principle which guided me in the presentation of this journey.

The chapters in this section alternate between those based on conventional qualitative research and those exploring the cultural or political background of their making. They ought to be seen as windows, or frames offering different viewpoints on quality of life in long-term conditions, interwoven around the thread of the deconstruction of quality of life's underpinning dualisms. The text of quality of life is indeed conceptualised as underpinned by five key dual oppositions in need of deconstruction: life and death, health and disease, dependence and independence, empowerment and disempowerment and certainty and uncertainty. The 'and' is used deliberately, to oppose a modernist framework that tends to see these concepts as being exclusively situated, in that one is either one 'or' the other. This deconstruction of oppositional pairs is both informed by and informs the different texts.

The interweaving and alternating of conventional research and textual focus is intended to illustrate, conceptually as well as structurally, two interactions. The first is the interplay between the subjective sense of self of an individual and his environment in the conceptualisation of quality of life. The BwO becomes, through such a nomadic journey, between territorialisations. The second concerns the territorialisation of quality of life as a concept and the interaction between its

territorialising forces. This section ought therefore to be seen as a textual voyage, in the spirit of a science that follows. Like a nomad, the reader is asked to enter each chapter, knowing that it will soon be time to move on. In as much as it is possible within the confine of the written word, this section attempts to provide a physical support to nomadism. It, however, has a beginning, in these few paragraphs, an end and clear links, although I hope to have left the space for many more to be established. This section can only therefore be (rhizomatic), in that it is inspired by Deleuze and Guattari's concept, but contains many more striations than their oeuvre.

The following pages aim to create a smooth space, in which quality of life can be apprehended differently. If the reader finds the structure of this section counter-intuitive, it is simply because we generally live in a state, structured space where things are labelled and ordered in a way that seems logical to us. I fear that too much signposting might influence the reader's journey, but some is offered throughout the section and a concluding chapter will hopefully ease some confusion. The dis-order used here is deliberate and crucial as part of the (rhizome), as it aims to promote a deterritorialisation of quality of life through the consecutive exposure to different data sources. The signposting offered is an attempt to reconcile my goal of undoing prior understandings through dis-order and the imperative need to make this piece of work readable and engaging. One such attempt to aid reading is the use of a different font for the deconstruction of quality of life's underpinning oppositional pairs.

The journey starts by exploring how *Pinocchio* can inform us on created popular assumptions about the health services and their relationship to the chronically diseased body and quality of life. Disney's animated feature is contrasted to the original novel, written in nineteenth century Italy. Pinocchio has an impaired body in that it is made of wood, which is inscribed by the medical discourse in searching for the cure of becoming a real little boy. Pinocchio is an animated puppet. As such, he is at once full of life and made to look alive. This leads to a deconstruction of the opposition between life and death.

The following step in the journey exposes quality of life through service development A. There, the emphasis is on the rationale behind the service



development and the ways in which this relates to its users' life. Institutionally, life quality is measurable, quantifiable and linked to present bodily functions, both in time and space. Individually, life quality sits within one's life history and social environment. This chapter introduces the notion of the MS-ised body as a new territory.

The opposition between health and disease is then deconstructed. This also serves as an introduction to the next step in the journey, as the representations of long-term conditions in popular television. Templates frequently used in television programming, such as freaks and villains, are exposed within the context of the representation of long-term conditions. These are presented as a template yet to be reversed and predominantly inscribed by a medical discourse that focuses on prevention and cure. This leads to a discussion of the notion of dependence and independence and the way in which they are conceptualised as oppositionally situated to one another.

The journey's next stop is at service development B. The focus there is on group attitudes and interactions during the MS physiotherapy intervention and on the embodiment of exercise regimes. Here, disowned bodies become active and talk about the bodily effect of feeling empowered. A discussion of empowerment, agency and disempowerment follows.

A political focus is then put forward, with the deconstructive analysis of the NSF for Long-Term Conditions (DoH 2005). It is provided as an exemplar of the political assumptions about life with a long-term condition, and focuses on notions such as independence and patient empowerment, as well as quality of life. It gives rise to a discussion on care pathways as territorialising devices, based on the prevention of relapses and impairments. This serves as introduction to the deconstruction of certainty and uncertainty-risk as opposed constructs. The analysis of the last MS physiotherapy study site (C) closes the journey. It provides an exemplar of the ideas put forward in the NSF and focuses on the idea of the defragmentation of services for people with MS. The analysis shows how this streamlining of a service may lead to a temporal fragmentation of its users' lives.

## **Walking without Strings**

This chapter relates Disney's *Pinocchio* and contrasts it to the original story, with a view to highlighting elements that are relevant to an analysis of cultural attitudes to quality of life in long-term conditions.

### **a. The birth of Pinocchio**

Collodi, born Carlo Lorenzini (1826 - 1890), was an Italian author and journalist who became best known as the creator of *The Adventures of Pinocchio*. The first chapter of *Pinocchio* appeared in the *Giornale dei bambini* in 1881. By the time Collodi began *Pinocchio*, his intellectual experiences embraced eclectically both literature and art forms (Wunderlich and Morrissey 2002). He had written for adults as well as for children, and the combination of these experiences is evident in the novel. Collodi was required to change the story radically half way through, as the puppet was meant to be hanged at chapter 15, but was called back by the magazine's enthusiastic readers (Zipes 1997). Reading Collodi's tale suggests an author sympathetic to the hard working poor, distrustful of human-made institutions and appreciative, within certain limits, of the carefree mind-set of unschooled youth.

### **b. The making of Disney's version, or Pinocchio's rebirth**

Disney's *Pinocchio* was released to American cinemas on the 7<sup>th</sup> February 1940. Based on the book by Carlo Collodi, it was made in response to the enormous success of *Snow White and the Seven Dwarfs* (1937) and was the second feature-length animated film to be produced by Walt Disney Productions. Feature-length animations have become the flagships of Disney's success and, as such, *Pinocchio* contributed considerably to Disney's powerful enterprise (Byrne and McQuillan 1999).

Though intended for the 1939 Christmas season, various delays prevented Walt Disney's *Pinocchio* from being released until February 1940. After five months production work, Walt Disney, unhappy with the work done so far, called a halt to the project so that the concept could be rethought and the characters redesigned (Street 1983). It was at this stage that Pinocchio was given a child's face as opposed to that of a puppet's, and that the character of the cricket was expanded. Jiminy Cricket (voiced by Cliff Edwards) became the sole narrator of the story. His song, *When You Wish Upon a Star* became a major hit, which is still identified with the film and was later used as a tune for Walt Disney Studios itself (Byrne and McQuillan 1999). *Pinocchio* won the Academy Award for Best Song and the Academy Award for Best Scoring of a Musical Picture. The film has been deemed 'culturally significant' by the Library of Congress, and was selected for preservation in the United States National Film Registry. The film was not distributed in Europe until 1947.

*Pinocchio* represents a technological breakthrough, one of the most visually and technically innovative of Disney's Classic films, and is considered by some to be his best feature (Wasko 2001). The film made extensive use of the newly developed multiplane camera, which allowed the animated frame to take on a reality through depth and perspective, closely approximating that of live footage (Zipes 1997). For example, one of the opening shots of Gepetto's village employed 12 different planes at a cost of \$25,000 (Wasko 2001). It was an expensive film, and costs escalated after changing the team and paying for technical ambitions to animate the movement.

**c. Disney's story as a metaphor for health care in long-term conditions**

The reading of *Pinocchio* that I wish to highlight here makes use of the metaphorical meaning of the being of a wooden puppet and the discursive trends that can apply to the health care system. The Blue Fairy (voiced by Evelyn Venable) acts as a medical expert, who firmly believes in the sanctity of life and often has the power to give or save lives. Like medical experts, she is not seen often in the film and people are respectful of her, her knowledge and her powers. Pinocchio (voiced by Dickie

Jones) has a long-term condition, characterised by a disability, that of being made of wood. I use 'disability' here metaphorically, as it connotes an uncertainty about the causes of his condition. Technically, he is not impaired, since he can do everything a little boy can, but aesthetically, being made of wood disfigures him. As the opening song suggests, if one is unfortunate enough to be made of wood, one should not give up hope of a cure, since "no request is too extreme", and "fate is kind" (Opening song, *When You Wish Upon a Star*). His condition is long-term, in that cure is uncertain. He has to *become* a real boy in his heart, before gaining human appearance. His impairment is therefore that, not having gained life through being born of a human mother, he has to prove to be worthy of humanity.

The Blue Fairy introduces the notion of individual responsibility very early in the feature, by advising Pinocchio that he should prove himself "brave, truthful and unselfish" in order to become a real boy. Her words mirror those of health promotion experts, who tell us to eat healthily, exercise and avoid any kind of substance abuse if we want to remain healthy. Through the Blue Fairy, *Pinocchio* precedes the moralistic discourses featured in current television programming. In giving life to the puppet, she fills a lack in Gepetto's life, but this is on the condition that Pinocchio fits an orderly ideal of the good son.

Jiminy Cricket, as Pinocchio's designated conscience, becomes an extension to the Blue Fairy's power. He can be likened to the health professional based in the community, who is in frequent contact with the patient and is able to provide him with guidance and advice. The Blue Fairy reinforces the role of the community practitioner in guiding people with long-term conditions, helping them to distinguish right from wrong for their particular circumstances. Jiminy Cricket, through his song *Give a little whistle* (whenever you face temptation), mirrors the availability of the health professional to those in the community who live with long-term health needs and might at any point face uncertainty or temptation. Like the community health professional helps ensure compliance to the consultant's advice, Jiminy Cricket is there to guide Pinocchio "along the long and narrow path to rightness". So while the goal of expert advice is to enable people to remain healthy, metaphorically, the aim is for the puppet to prove his moral worth in terms of honesty and righteousness.

Gepetto (voiced by Christian Rub) is Pinocchio's father, since he carved the puppet. As such, he is loving and devoted to his son's well being, but has very little role to play in the subsequent adventures of Pinocchio until the end of the film. Here again the film emphasises the concept of individual responsibility: only the patient can decide the path he or she will choose, independently from their family or social surroundings. Pinocchio's status as a child is uncertain. He has the features, attitudes and naivety of a child, yet he is to take responsibility for his father's wish to come true. He is responsible for the attainment of a cure for his puppet condition.

Like all good boys, Pinocchio is made to look smart for his first day in school. However on his way a fox, Honest John (voiced by Walter Catlett) and a cat, Gideon (voiced by Mel Blanc), convince him that school is not the best way to success. Honest John and Gideon can be likened to advertisers, appealing to the consumer in any one of us wishing rapid material success. Yet here again, there is an uncertainty, as while Honest John and Gideon are portrayed as themselves greedy for easy money, they indeed propose the most sensible occupation for a live puppet. If Pinocchio has a long-term condition and has to learn to live within the limitations of his wooden condition, then working in a puppet show would become a natural occupation. It would enable him to use his body as it is, to all its extraordinary capabilities, rather than wish for an unlikely flesh. So what the film tells us at this point is that there is no path other than the 'right path', which is to go to school to become a real little boy. Yet Pinocchio could have chosen an alternative path and become an accomplished live puppet. The theatre, in the person of the cruel Stromboli the puppeteer (voiced by Charles Judels), is demonised as being the path taken by naughty boys, who deviate from that shown by their Blue Fairy and who do not listen to their conscience.

For the duration of his first show, Pinocchio is left to enjoy his quite exceptional body and to sing the freedom from strings that other puppets do not have. Yet he and we live in a culture where perfection, whatever this may be, is to be sought. Pinocchio is not to learn to appreciate and grow within his newly found bodily situation; he is to conform to the norm, go to school and hope to become a real little boy. Jiminy Cricket sits in the audience, realises how successful his little companion

is and revises his judgement: maybe, after all, he was wrong and the theatre is the way forward for Pinocchio. In doing this, he fails in his role as a conscience. Being close to Pinocchio, he has come to understand his viewpoint and lacks the distance to provide 'sound' advice. Like health professionals who may work in close relationship to their patients with long-term conditions, he has come to see Pinocchio within a different paradigm, that of his bodily possibilities, rather than limitations.

Yet this is not the way Disney's story goes, for at the end of the night Pinocchio is made prisoner by a cruel and greedy Stromboli, who tells him in his heavy Italian accent how "sensational" and "colossal" he is, while counting his money. Stromboli seizes him and locks him in a cage, claiming that he now owns him and will "tour the puppet around the world" until he can no longer work and then will "chop him up for firewood". Here is the flip side of Pinocchio's quick success: a lonely cage away from his father and in the hands of an avid and unsophisticated traveller.

In the metaphor used here, Stromboli can be likened to a fast food, cigarette or alcohol manufacturer, who would have paid a substantial amount of money to advertisers - Honest John and Gideon - to bring customers, or indeed a new star, to his show. Pinocchio is not so much the consumer as he is the product to be sold in the shape of the show. He has succumbed to the temptation of quick success and in doing so ended up on the wrong side of the stage. To embrace an actor's career is to seal his fate as that of a failure to become a real boy.

Thankfully, as he watches the caravan pass by, Jiminy Cricket decides to jump on, to say good bye and wish good luck to his little companion. He tries unsuccessfully to open the padlock that keeps Pinocchio in his cage, when the Blue Fairy appears in the caravan: "Pinocchio, why didn't you go to school?" The emphasis is on institutionalised and organised, rather than experiential, learning. Pinocchio could have learned much about life and grown in maturity while being an actor, but this is not a form of knowledge valued by the Blue Fairy. Ashamed of his disobedient behaviour, Pinocchio tells the Fairy that he met "two big green monsters" on his way to school, but is interrupted by his nose growing through the bars of his cage. The

more he lies, the longer his nose becomes, to reach a point where leaves grow on it and a nest with two birds appears on its tip.

During this episode Jiminy Cricket, as the practitioner who works in close relationship with his patient, displays his familiarity by calling the central character “Pinoke”. His style is informal and he appears to be both on the side of the fairy (“you’d better come clear”) and on Pinocchio’s, by interceding for his pardon. Like other practitioners who work in close relationship to their patients he is the go-between, connecting the medical expert as the keeper of a much-respected knowledge and power, and the patient, as the naïve and easily tempted being who might at any point choose the wrong path.

The Coachman (voiced, like Stromboli, by Charles Judels) is introduced at this point, as an evil character involved in child abduction, who seeks to subcontract Honest John and Gideon to recruit idle little boys. Like the terrible Stromboli, he can be likened to, for example, cigarette manufacturers who will subcontract the advertisement of their product. Once introduced to the product, people never come back the same and are indeed labelled as ‘ex-smokers’ on their life insurance policy and their medical records. The Coachman assures Honest John and Gideon that they cannot get caught, for the boys “never come back”.

Pinocchio has been on the slippery slope of wrongness and is now determined to become an educated and real little boy. Unfortunately, he gets stopped again on his way home by Honest John and Gideon and candidly relates to them his misfortune with the puppeteer. Honest John is quick to pick up on this:

HJ: “Oh, you poor, poor boy. You must be a nervous wreck... We must diagnose this case at once.” He clears his throat, puts his glasses on, and takes Pinocchio’s pulse. “Bless my soul – Hmmm, mm-hm, my, my. Just as I thought... A slight touch of monetary complications with bucolic semi-lunar contraptions of the flying trapezes.” He then looks into Pinocchio’s mouth, keeping it opened. “Mm- hm. Say ‘hippopotamus’”.

P: “hi-ho-hotamus”.

HJ: “I knew it! Compound transmission of the pandemonium with percussion and spasmodic frantic disintegration. Close your eyes. What do you see?”

P: "Nothing".

HJ, putting a dotted cloth in front of Pinocchio: "Now what do you see?"

P: "Spots".

HJ: "Aha! Now that heart". He lifts Pinocchio's shirt and puts his ear to the puppet's chest. "Oh my goodness" He says while tapping with his cane on a window frame behind him, and continuing in rhythm: "A palpitating syncopation of the killer diller with the wicky wacky stomping of the floy joy. Quick doctor, that report!" Gideon passes on his scribbles. "Oh! This makes it perfectly clear. My boy you are allergic".

P: "Allergic?"

HJ: "Yes, and there is only one cure: a vacation to Pleasure Island; that happy land of carefree boys where every day is a holiday!" To Pinocchio's protests he objects: "tut-tut-tut-tut, I insist, your health comes first".

This section reflects how much of a concern health is to people and how ready they may be to be led astray through seemingly scientific discourses. This teaches us to be wary of any health related advice that comes from other sources than those officially accredited and recognised by our health services. We, as patients personified by Pinocchio, are portrayed as lacking the judgement to discern between laudable health arguments and ones motivated by profit only. Advertisers are portrayed as being cleverly able to use a pseudo-scientific discourse to confuse us.

Pleasure Island, which was sold as a remedy to stress, turns out to be a place of debauchery, where all the rules Pinocchio has to follow to become a real boy are broken. Smoking, drinking and getting involved in violent acts ultimately would have led Pinocchio to slavery. This reflects what health promotion experts tell us, as if we give in to temptation, we may become addicted and therefore slaves. The metamorphosis into a donkey is the transformation into people with ill health, who might then find themselves excluded from mainstream society – working in a salt mine. Only a timely intervention from a health care professional may save us. A hierarchy of ills is displayed here, since if being a life puppet is not valued, a wrongful attitude can lead to the transformation into the subhuman state of donkey and slave.



Pinocchio and Jiminy Cricket escape and run home to discover, through a message sent by the Blue Fairy, that Gepetto, in his search for his son, has been swallowed by a whale. Its name is Monstro and it lives at the bottom of the sea. Pinocchio decides at once to go and rescue him and Jiminy Cricket follows. They jump in the sea and start their search for the terrifying Monstro. Disney tells us that Gepetto has been swallowed whole with his boat and has been kept alive by fishing in the whale's belly. He therefore depends on the whale feeding for his own survival. Just as he thought he was running out of food, a current of tuna fish enters the cavity. Pinocchio is amongst them and having found his father, decides at once to develop a plan to get out of the whale. They light a fire to make Monstro sneeze and manage to get out on a raft. They narrowly escape the whale's wrath, as Pinocchio swims towards the shore with an exhausted Gepetto on his back. They are projected on the rocky shore, both unconscious, Figaro the cat, Cleo the fish in its bowl and Jiminy Cricket nearby. The following scene shows Pinocchio unconscious on a bed, Gepetto praying at his side. A bright light appears and when it dissipates Pinocchio is a real little boy. Everyone celebrates and Jiminy Cricket is awarded a gold medal reading 'Official Conscience'.

So although Pinocchio did not go to school, he became a hero by saving his father. In doing so, he showed he was capable of unselfishness and bravery, but also of love and dedication. When one is capable of such noble emotions and actions, one is rewarded. This secularises a superior Justice, which implies that people get what they deserve in life. In this, Disney's *Pinocchio* echoes discourses of individual responsibility in health care and does not account for the millions of virtuous people who live either in poverty or ill health. Disney's *Pinocchio* leaves these people to hope for a solution, for a cure, and does not help them to explore new possibilities within their life condition.

Now that the reader is familiar again with the story and has an insight into the possibility of a health reading of the feature, let us see if this stands up to the scrutiny of a more in-depth analysis. This will place Disney's *Pinocchio* back into the historical and cultural context in which it has been made, and then imported in Europe, and compare it to Carlo Collodi's original novel.

#### **d. Collodi's vs Disney's *Pinocchio***

Street (1983) and Zipes (1997) systematically and succinctly contrast the two versions, arguing on behalf of Collodi's story and against Disney's film and situating the movie in its context of corporate culture and imperatives. Although the film has been analysed by these authors in particular for its social and cultural significance (Wunderlich and Morrissey 2002), it is its relevance to the health services and our cultural attitudes to health and disease that is of significance here. In the following paragraphs I will attempt to place Collodi's novel and Disney's animated feature back in their historical contexts, looking at and comparing them through health related lenses. Disney's *Pinocchio* has some commonality with Collodi's novel. That is to say, very little, but not absolutely nothing. To compare and contrast the two versions will highlight elements of the socio-political health care contexts that saw their making and made their success.

#### ***Historical contexts***

Wunderlich and Morrissey (2002) describe Disney's *Pinocchio* as the antithesis of Collodi's original puppet, while acknowledging the success of this new version. They describe a change of attitude from the public, from one that enabled the success of Collodi's *Pinocchio* until the 1930s, when the tale reached America, to one that considered it as an adult version of Disney's animated feature. They attributed this change to the decade-long Great Depression in the United States. Unemployment, poverty and alcoholism were endemic, often forcing families apart. For some, crime was the only way to survive and even succeed in these hard times. In order to stop children from engaging with the heroic gangster type, various movie production codes in the early 1930s required that there be no disrespect for law enforcement, no glorification of gangsters and that outlaws would always come to a bad end (Bergman 1992). In addition, Charles Eckert points out that "politicians directly charged Hollywood with the task of 'cheering Americans up'" (Eckert 1974: 165) and light-hearted musicals were a favourite of the time.

*Pinocchio* was only released in Europe in 1947, two years after the war, and at a time when the societies of Europe had similar needs for hope and escapism to American people seven years earlier. People were poor and Governments needed hope to be

injected back into the population for a new, peaceful Europe to be built. In the UK, while the Dunkirk spirit of 1940 and the air raids led to a sense of solidarity; evacuation made many aware for the first time of the extent of poverty and ill health among the urban working class. The euphoria of Victory Europe and Victory Japan Day did not signal a bright new dawn of health and happiness for the people of Britain. The bombing raids ceased and the troops gradually returned home, but day-to-day struggles associated with the war continued. In July 1946 bread rationing was introduced for the first time. Rationing, which did not disappear completely until 1954 (Jones 1994), lowered spirits and contributed to the dullness of post-war Britain. The Government was aware of the importance of sustaining both morale and an efficient workforce.

In many respects, the NHS was born out of a consensus peculiar to the war (Jones 1994). In 1941 the Beveridge Committee on Social Insurance and Allied Services was set up to review the question of unemployment and health insurance. When the Beveridge report appeared in November 1942 (Beveridge 1942), it recommended the establishment of a comprehensive welfare state, based on subsistence rate benefits 'from the cradle to the grave'. This idea was taken up in the 1944 White paper (Ministry of Health 1944) on the Future of the Health Services, which established the basis for a free and universal health service. The first contingent event in the creation of the new NHS was the election of the Labour government in 1945. The NHS was seen as the flagship of post-war British socialism and as such attracted both the antipathy of much of the Conservative party and the medical profession, as the NHS Bill was passed in 1946. The NHS Act became operational in 1948 (Jones 1994). So it is right at the time of the making of the NHS and amongst all the disagreements and debates surrounding it, that Disney's *Pinocchio* appeared on the screens of Britain.

At the same time, from the middle of the war, a subtle change on health broadcasting began. For example, at the repeated request of the Ministry of Health, the BBC started running talks on diphtheria immunisation (Karpf 1988). Such public health programming encouraged listeners to use the state medical and health services that were the forerunners of the NHS. At the time, the British Medical Association

(BMA) also lobbied the BBC to give more space to the opinions of the medical profession (Karpf 1988). In the late 1940s and early 1950s the form of health and medical programmes was also changing. There were now three radio networks and a growing number of discussions with more spontaneous speech, though almost all featured health and medical experts and avoided criticisms of medicine (Karpf 1988). Wunderlich and Morrissey (2002) assert that Disney eradicated poverty from Collodi's novel. I would argue that it also eradicated disease and disability. In Collodi's tale, poverty means no money and not enough food. The young Pinocchio is often hungry and when at one point he is too fussy to eat all his fruit including peel and core, he gets a lesson from Gepetto for not wasting food because a next meal may not be guaranteed (Collodi 1968). While good practical advice after the war, some might have found the lesson too harsh a reminder of people's circumstances. Under these conditions, fantasy dwelling on what one would like to have could be far more soothing. People needed strong and healthy bodies to go to work. Men were now back from the war and needed to provide for their family. So *When You Wish Upon A Star* is not only about wishing wealth, it is also about wishing healthy and productive bodies. It offers a consumerist conceptual framework for the reification of an improbable good and happy life.

Wunderlich and Morrissey (2002) state:

The substantive changes in Collodi's vision by Disney are consistent with efforts to remove from public entertainment ideological impurities, replacing them with an acceptable vision of abiding citizenship. The impact of this re-visioning of Pinocchio cannot be understated. After 1940, Collodi's story gradually became *a version of Pinocchio*, and not *THE Pinocchio*, and the new images compatible with an invisible, default ideology became dominant and to this day continue to do their small part to support soothing, status quo images of parents, children and society (2002: 110, emphasis in the original text).

This is applicable to the post war UK context of increased concern for health care and the birth of the new NHS. Politicians and the medical profession alike needed people to become more health aware and trusting of the medical establishment. Conveniently at that time, Disney's *Pinocchio* presented the means to contribute to an acculturation of children into trusting and compliant patients.

### *The acculturation of children*

Disney's version is aimed at children, in order to contribute to their acculturation and moulding into health aware and complying patients. Using the family as metaphor, the new *Pinocchio* portrays the health services (the Blue Fairy and Jiminy Cricket) as compassionate and benevolent and urges patients (the puppet) to have faith in its decisions and policies. And although some community health professionals might occasionally mishandle situations, they can always be trusted to have the patient's best interest at heart. The patient should feel in harmony with the health services and their representatives, for that is the natural order.

In Collodi's story, in true fairy tale style, the wood that Pinocchio was made from was able to talk and be mischievous long before the carving of the puppet. The fairy does not animate Pinocchio, but rather serves as a wise counsellor who presents herself first as a sister and, later, a mother. As such, whilst she is always there for Pinocchio and forgives him all his misdemeanours, she does not hold the authority of Disney's Blue Fairy as the giver of life, whose orders have to be followed without question.

The image of home life Collodi provides is starkly different from the one painted by Disney. Collodi discloses a very natural tension between parent and puppet and over many pages, leads both of them to confront and resolve their disputes. For Disney, there are no tensions. Collodi's puppet is headstrong and active, vibrantly confronting, taking risks and plunging into life. His newer counterpart is largely docile and dependant on others for direction. Both Collodi (1968) and his puppet are cynical and even mocking of significant authorities. For example, when the Blue Fairy asks doctors' advice about Pinocchio's state of unconsciousness, they reply:

To my belief the puppet is already quite dead; but if unfortunately he should not be dead, then it would be a sign that he is still alive! Says one doctor. "I regret," said the Owl "to be obliged to contradict the Crow, my illustrious friend and colleague; but in my opinion the puppet is still alive, but if unfortunately he should not be alive, then it would be a sign that he is dead indeed!" (1968: 78).

Collodi's puppet must learn which authorities are worth following and which are to be obeyed pragmatically or even disobeyed, and that the decision is an active and

moral choice on his part. This is not the case of Disney's puppet, whose attitude is to be respectful and trustful of all authorities.

Honest John and Gideon lure Pinocchio away from the right path to lead him to Pleasure Island, based on concerns about his state of health and stress. This is a complete addition to the original novel, which is coherent with the authorities needing the masses to become more health aware and introducing the notion of individual responsibility in health. In Collodi's vision villains are sociopaths and predatory and heroes often leave much to be desired. It is a world where civil authority is impotent or corrupt, where hunger is a given and death the ultimate fact of life. This is completely at odds with the message of trust and public health that the new government would have wanted to be broadcast just after the passage of the NHS Bill. Disney's version is so much more in keeping with the general political mood of the time than Collodi's tale. The government needed children to grow up into health aware adults who would use and trust the medical establishment within the new health services.

Another crucial difference is that in the original novel the puppet becomes a donkey following a five month stay on Funland, and has, for a while, to *be* a donkey, first working in a circus and then for a milkman. This is in stark contrast with Disney's *Pinocchio*, where the boys' metamorphosis into donkeys happens overnight and where they are sent to labour in salt mines. They are sent away to a world that the spectators are likely to be unfamiliar with and, in that, they are excluded from the society they have known so far. This is not the case in Collodi's story, where they remain part of the society they have known thus far, only under a different form. There again, Disney's message reinforces the absolute necessity to follow the right path at all times, on pain of social alienation. The donkeys symbolise difference and otherness, which, in Disney, belongs to another world, but which is very much part of society in Collodi's novel.

Disney makes Pleasure Island, as a quintessentially wrong path, even more fearful by crafting an image strikingly different from Collodi's description. As Street (1983) notes in his comparison of the film and novel:

Collodi's boys are living out the ultimate childhood fantasy – escaping to a schoolless land of never-ending fun and camaraderie; while Collodi shows that the results of such behaviour are personally destructive, the fun itself is not. Lack of education and guidance leads in the novel to childish play and idleness; for Disney such behaviour leads to a corruption of morals, wantonness and vice, gluttony, fighting, and eventually disfiguration and death (1983: 55).

Collodi's world is not at all fundamentally sinister, despite its corruption. It allows manoeuvrability and permits many natural helpers along the way. Disney's world does not provide such helpers: the Blue Fairy intervenes directly on only one occasion and Jiminy Cricket, except for advice and support, is too tiny to intervene. Disney's outside world is not for children. Metaphorically, the world outside of the health services is not for people with health concerns and children may as well grow up believing it.

Collodi accepted, and indeed cherished, his hero in his puppet form and made him achieve a state of being that would seem to have earned him humanity without requiring an actual change in form. This is a paradox that is not carried over in Disney's animated feature, and that is telling of a non-acceptance of the 'other'. In Disney, Pinocchio is subjected to an ontologisation as a rejection of otherness, highlighted by the fact that the puppet's difference causes him to be exploited by Honest John and Gideon. His metamorphosis at the end of the film is the final triumph against puppethood. So children are to aim to become compliant and obedient, trusting of authorities and are to fear the wrong path and wish for bodily perfection.

#### *A journey to become other*

Collodi's puppet unintentionally embarks on a journey of self-discovery and self-actualisation, one described as an epic journey from childhood into adulthood (Wunderlich and Morissey 2002). This, of course, is not particular to human growth, but can refer to any journey to become 'other'.

Unlike other famous Disney characters, Pinocchio represents a crucial undecidability between life and death. As an object, he is inanimate and not alive. In his journey to become a real boy, he is first animated into a talking puppet. To animate is to give

life or to inspirit; to be animated can either mean to be full of life or its opposite: to move as if alive. As a wooden puppet, the materiality of his body resists organisation and because of that, he is not alive and therefore could be dead. While Collodi's puppet is full of life, with all the contradictions that entails, Disney's puppet is made to move as if alive, in a transitional non-state of waiting for boyhood. This is also the non-state of people with long-term conditions: not healthy and sometimes not full of life, they are in a transitional period, waiting for cure or death (Murphy 1987). Murphy asserts:

The long-term physically impaired are neither sick nor well, neither dead nor alive, neither out of society nor wholly in it. They are human beings but their bodies are warped or malfunctioning, leaving their full humanity in doubt. They are not ill, for illness is transitional to either death or recovery. The sick person lives in a state of social suspension until he or she gets better (1987: 112).

In Disney's film, the ultimate goal is the flesh-isation and organ-isation of the puppet. This can be achieved in following expert advice that has moral overtones, as the puppet has to prove his sense of courage and morality. As a result of this, bodies that are organ-ised and not impaired belong to righteous human beings. An organ-ised body is organised through a scientific discourse represented by the Blue Fairy, which does not engage with the wooden body-without-organs. Like those people with non-curable diseases, Pinocchio's body is subjected to a series of often debilitating transformations, like nose growth or his part metamorphosis into a donkey.

In Disney's *Pinocchio*, there is a clear cause to effect relationship between the puppet's actions and the misfortunes of his body. This echoes the explanatory power of the scientific discourse of cause and effect, and does not reflect Collodi's story. There, Pinocchio's nose occasionally grows when he is truthful and sometimes it does not grow when he is not. His nose can grow so big as to stop him getting out of a room, becoming a real impairment. Collodi's world is more complex, more difficult to apprehend for the puppet, but also offers more possibilities. It is a smoother, less striated space, where the explanatory power of emerging situations is limited. In contrast, Disney's Pinocchio is made directly responsible for his bodily misfortunes, in a very Manichean manner.



In Collodi's novel, Pinocchio's nose relates to people with long-term conditions both in a bodily sense of loss of control over what is happening to one's body and of the factors that may motivate, for example, self-care decisions. The self-care decisions that a person with a long-term condition may be driven to make are not simply good or bad. Rather, a whole array of actions may have consequences of varying degree and extent, depending on the circumstances. In Disney's world, a responsible decision can only be made on the basis of expert knowledge. This suggests that a decision can only be reached with a determinate amount of knowledge, which limits the responsibility of making a decision (Byrne and McQuillan 1999). The nature of the 'right' and the 'wrong' paths as shown by Collodi, are as undecidable as Pinocchio's status as a living creature. What is right in a certain place at a certain time might be totally inappropriate in other circumstances. Like a physical and metaphorical BwO, Collodi's puppet grows and becomes in a complex dialectical relationship with his environment.

The protectionist attitude of Disney's *Pinocchio* towards children can be likened to that of the health services towards people they see as dependent and vulnerable. In Collodi's novel, boyhood is not a cure, or an end, but only a step in a life that will not be perfect ever after. Pinocchio becomes more mature as he learns lessons, but his journey does not end with boyhood. So the goal for Collodi's puppet is to find the conceptual BwO that will enable a series of deterritorialisations and reterritorialisations. Pinocchio learns by trial and error and by matching his errors with the words and actions of those more experienced. He learns that some people are more trustworthy than others, but that no one can have all the answers to the challenges of living in an imperfect world with a body made of wood. Pinocchio must make choices because all humans, when faced with life's challenges and opportunities, must be able to choose wisely. At the same time, neither he nor we are fully autonomous and our choices have boundaries.

With Disney, Gepetto loses his original temperamental personality. Pinocchio now fulfils the old man's longing for a son and their family is portrayed as loving and naturally harmonious. The puppet only disrupts this harmony unintentionally because malevolent people prey on him. Wunderlich and Morrissey state:

In the end this new puppet is changed into a good boy, *but not into a young adult*. In this new imagery no longer is the child's goal to grow up, mature and transform. Rather, its goal is to be a good child, a loved and commended child, a child who enhances family harmony and promotes family solidarity. *Its goal is to continue as a child!* (2002: 86 Emphases in the original text).

So Pinocchio's growth is limited in Disney's feature to the boundaries imposed by the authorities. Pinocchio is territorialised as a good child in a scientific and moralistic discourse that relates his righteousness to his flesh-isation. Collodi's puppet becomes a young adult, responsible and providing for his ageing father and the Blue Fairy, who is in hospital. His flesh-isation is a by product of the BwO that enables him to respond to life's challenges in a creative and responsible manner. There is no such sense of responsibility in Disney, as the boy is to remain a boy and responsibility is to remain in the hands of the experts.

Paradoxically, the contrast between Collodi's *Pinocchio* and Disney's is that between a BwO, as conceptualised by Deleuze and Guattari (1972), and the body as described by science. What is paradoxical is that while Collodi wrote in nineteenth century Italy, his novel is, in the sense explored here, post-modern. Disney's *Pinocchio* is a celebration of dichotomy in an era dominated by experts. Collodi's world was as corrupted and harsh as it might have been in America during the Great Depression. But his vision is one that exposes the possibilities of a body in a less than perfect world. Perhaps unknowingly, Collodi produced a novel that celebrates difference, not by *classifying it as right or wrong*, for example, but by exposing the territories we all have to manoeuvre through and the possibilities of deterritorialisation.

## Life and Death

To talk about quality of life is to assume the difference, if not the opposition, between life and death. The following paragraphs examine this assertion. The time of quality of life is often perceived as linear, going from birth, life, disease and, eventually, death. This is both a conceptual relationship, in that life and death are not only oppositionally, but also hierarchically, situated and a relationship in time. Life happens before death and death often happens through disease. Death is related to feelings of finitude and impermanence that human beings have transcended through ritual burials or architectural wonders, for example (Adams 2006). So ultimately, our negative perception of quality of life in long-term condition is linked to our rejection of death as an ineluctable individual ending. As the doctors in Collodi's (1968) novel, *Pinocchio*, suggest rather humorously, one can only be considered alive when not dead. Therefore the verification of death becomes the negative definition of life itself. Politically and historically, life has been managed through the administration of death (Rose 2001).

Whilst it was once common to decide that someone had died because their heart had stopped beating, this is no longer an acceptable cause of death. Armstrong (2001) explains how as it gained expertise, medicine came to classify people in categories, so that everyone was normal, yet no one was truly healthy. He describes how death had been for a long time perceived as coming in the shape of a black-coated figure to mark the end of life. "Such deaths were natural in as much as it was nature that came to reclaim her own" (2001: 146). Medicine later transformed this natural death into a pathological one: death was no longer coming from the outside, but was contained within life from the moment of conception (Marshall 2006). Within this framework, long-term conditions are the black-coated figures highlighting the vulnerability and impermanence of the body. Morris asserts: "Death is a scandal in postmodern times, partly because it unmasks the illusion that we can live for ever" (2000: 15).

If death is a negative definition of life, one might wonder about the conceptual and temporal boundaries of death. Survivors of near death experiences describe dying as waking up from a dream, the dream being the physical life we know. Sweeting and Gilhooly (1992), describe

the existence of three types of death in the literature; clinical death, biological death and social death. For some people, for example in late stage dementia, in the final stages of a terminal illness or very old people, social death may happen before physical death (Young et al. 1999). In Hindu philosophy, the self is eternal and merely passes from an embodied life to another. Buddhism defines the notion of 'rebecoming', as a process seen through life and not only at the point of death. This process continues beyond death when the karma generated by the person's actions has not yet yielded its results (Thompson 2003). Some Eastern systems of thought may therefore see life and death as more fluid and interrelated entities, which happen more to social groups than to individuals.

The question of what death is and whether there is life beyond it is also linked to the Cartesian belief in mind and body separation. Death is the death of the body and, depending on one's beliefs, the essentialised self may survive in some form afterwards. But if that is untrue, and if our mental processes are entirely defined by biological pathways, then death is an absolute end. That is, until science finds a way of freezing the body to revive it when it is technically possible to fix what was wrong with it. The recent technological advances that enable the cells of one's own umbilical cord to be frozen with the view of curing future diseases, is a start of this process. The cells that enabled the life to emerge in the first place, but were then defined as waste product, may now be used later to maintain it and delay death (Cooper 2006; Turner 2006).

The beginning of life is as uncertain as its end and debates about it have been raging in medicine, philosophy, ethics and law for decades. At the moment of conception, two gametes join to create a fertilised egg. A new organism is produced and from this moment on, if a linear model of time is accepted, it will develop according to its genetic make up, until it reaches full maturity and slowly starts to decline. The ethical and philosophical dilemma rests on the decision of the timing of when a few multiplying cells become a human being with a right to live. The limits between life and non-life are being fiercely disputed between advocates of the abortion and anti-abortion movements, for example. There is no consensus concerning when conscious life begins. But this is not the only example of blurred and shifting boundaries between life and non-life or death. In a healthy organism, on an hourly basis, dead cells are shed in a continuous cellular renewal process. However, curing cell death may lead to cell cancer, further blurring the boundaries between the determination of life and death.

Cell death has been described as a predetermination of the life-span of the whole body, until the advent of stem cell research (Cooper 2006; Marshall 2006). Indeed:

stem cell research homes in on the points of non-coincidence between aging in general, and the body's multiple reserves of renewable tissue, uncovering a kind of latent 'surplus' life, even in the most worn-out bodies (Cooper 2006: 3).

For example, umbilical cord blood is now being commercialised as a source of future hematopoietic stem cells for patients who would otherwise require a bone marrow transplant. Stem cells are therefore the epitome of the limit between life and death and embody the possibility of a never-ending healing potential. On the scale of a whole organism, the sudden death of someone often enables life in another body, through the donation of organs and their subsequent transplantation.

Philosophically, if one is to embrace the principle of sanctity of life, then one believes that it is morally wrong to end life. But spatially, where does life end? While in Western societies life lies primarily within the individual body, the Confucian Chinese belief of personhood extends to the family and intimate social circle. Similarly in Japan, the closest translation for the term 'person' is 'human between-ness' (Kirmayer 1988).

On an individual level, philosophically and ethically, the right to die is as disputed as the right to live. Often, quality of life is used as a decisive argument throughout the life-death spectrum. On a micro, as well as on a macro, scale life and death are part of life, in a dynamic movement that pertains to the order of things and itself is life enabling. Then again, within a consumer culture, that has created the body as a "passport to all that is good in life" (Featherstone 2001: 234), it is hardly surprising that ageing, long-term conditions and death are viewed so negatively. They are unwelcome reminders of the inevitable that is in store, even for the most virtuous and health or body-conscious individual. While traditionally the body may have been conceptualised as a transitory vehicle to a higher spiritual end, this has been superseded by its secularisation. Featherstone asserts: "the consumer culture imagery has decreed that life can and should be everlasting happy" (2001: 234-235). Long-term conditions do not fit easily into this imagery. "Disabled people are seen to be ambiguous because they hover between humanity and animality, life and death, subjectivity and objectivity" (Shakespeare 1994: 295). While people with long-term conditions may not always display visible signs of impairment, they are conceptualised in a similar manner. They exist in

an in-between non-state that challenges the dualities of the Enlightenment. Pinocchio, in his non-state of live puppet who is not dead, but yet not real, epitomises the non-state that people with long-term conditions can find themselves in.

So life and death are not as clearly delineated or as oppositionally situated as often assumed in Western thought. Life enables death as any life contains in itself the programming of its own end. Death enables life through a renewal process at a cellular and population level. *How much* life we can have is determined by our time of death and this time-span remains the focus of the health care enterprise. The contemporary discourse on quality of life to a certain extent, questions this sole focus.

Life is undetermined temporally, socially and conceptually and is framed by an equally disputed notion of death. It may be that quality of life challenges the medical ethos of preserving a mobile and healthy life, by requiring a shift of perspective, or a deterritorialisation, from an absolute life / death dualism to one that learns to accept and appreciate life in its multiple forms and stages.

## **Health service provision, rurality, MS and quality of life**

In their proposal to the MS Society, the service developers introduced area A in a way that emphasised geographical isolation as a central problem. Implicit in the design of the service is the assumption that people in the area feel isolated, that there are some inequities in people's access to health services and that this has a negative impact on their quality of life. The physiotherapist's (Tim) post offers the possibility to reach people deemed geographically isolated and bridges gaps between professional practices. At the core of the text of this service are the assumptions that people with long-term conditions have a poor quality of life, that people feel isolated when they do not have access to physiotherapy and that a better provision of physiotherapy will have a positive impact on people's lives.

### **a. Living with an MS-ised body**

An MS-ised body is one that is territorialised by the medical discourse as a sole function of the micro-happenings of its neurological system. Long-term conditions are defined through their relation to time. MS is long-term in its duration ("it's like living a life sentence" – Justine) and constant impact on people's life: "MS (is) a constant thing... I've managed to get out of the bed, I got to the shower, had myself a shower ... a lot of people can't do that. I got myself dressed. I managed" (Peter). Time enables the disease to progress in spite of diverse health service input and the body is on an ineluctable course, set by its internal MS related micro-happenings. I met Peter once before and once after a series of physiotherapy sessions with Tim. He was diagnosed in the 1980's, but believes he has had symptoms since his pre-teens. At the time, neither he nor his family had ever heard about MS. As a result of those circumstances, he has grown up with the disease and it forms an intimate part of who he is. Peter uses an automated wheelchair and although he would have been a very tall man, he now cannot sustain the weight of his upper body and looks folded on himself in his chair. He places a lot of importance on his family and comes across as a very happy, cheery person.

Over the years, Peter has had to come to the conclusion that health services were not able to better his condition: "I've done a fair bit of OT in the earlier days. It came to a point where it wasn't really producing anything. By mutual decision, we decided to abandon it." What they could do was reduced to a "contraption here and there, a sling over the top of the bed", in spite of which the disease continued to progress. So the time spent in contact with health services has led him to deterritorialise himself from his patient position and present himself as a coherent whole, with a body over which he has very little control. The chronicity of his condition and the length of time he has spent in contact with the health services has enabled him to self-realise, beside his body.

Stuart and Moira participated in the study as a couple. Although he was present for the interview, his speech being severely impaired, he nodded and added an occasional comment, while Moira contributed most of the talking. She seemed to devote her life to the care of her husband, who is severely affected by MS. Stuart's biggest MS related problems are the tremors of his upper and lower limbs, which prevent him from doing the exercises he would need to do to strengthen his muscles and regain some control over his movements.

The spasms are the worst thing really. That is his main difficulty. Sometimes they are going...really all day. He takes [anti-spasmodic drugs] but sometimes it just does not do anything you know. But with some physio they stretch it and all of this... It definitely works wonders... (Moira).

During the interview, the couple explained how Stuart's malfunctioning body and its routines of care are at the core of their family life. It is MS-ised through the constant-ness and progression of the disease, through professional discourses, which are the source of this MS-isation and through the place MS takes in their immediate environment.

To address Stuart's tremors, the couple have agreed to an implantation of electrodes in his brain. At the time of my visit, he was recovering from the operation. They both placed a lot of hope in this intervention, but felt that before it, they had worked really hard improve his muscle tone and flexibility. He was progressing a little, until he went to hospital, where he was left relatively immobile for days. So at the time of



interview, they were feeling like they had to start all over again; hoping that the operation would have changed things for the better overall.

It's going back in intensive care that's done it [he has lost all strength in his lower limbs]... He got no physio in hospital; none at all. I mean Stuart's the way Stuart is, he should have had somebody coming on a daily basis like I was doing. I was doing [movements] there... But really it should not have been me at all... (Moir).

During the stay in hospital, the MS-ised body is fragmented in body parts, as while the medical focus was on his brain, the rest of his body was left to its own devices and he lost the strength painstakingly regained over the previous few months. Making the malfunctioning part of the body function more 'normally' and stop the tremors so that he may be able to hold a cup and maybe even feed himself, is the medical endeavour. It derives from this that for the couple, while medicine creates the MS-ised body in a technical way that both offers hope and disempowering fragmentations, physiotherapy helps them explore the territory of this MS-ised body.

#### **b. Quality of life conceptualisations**

Jim, who was diagnosed five years prior to the interview, describes his life as minimally affected by MS. He appears fit and healthy and describes how he only had to pace himself to accommodate his symptoms.

-ML: Do you think there is any way that services could impact on your quality of life...?

- Jim: Me personally I think no, I don't think there's anything else they can do. I'm still at work. Paying bloody income tax! There's nothing they can do for me that I know of... there's nothing I need. I'm all right.

Jim implies the distinction between what health services can do for his body - in his case nothing because, functionally, he is well - and the way in which they cannot impact on his quality of life. Like Peter, he uses a mechanistic view of the body in order to resist the power of the medical discourse. People remain in charge of what is important to them and their quality of life, beside and beyond their MS-ised body. Jim also uses an economical discourse, implying that the body that is well enough to work and therefore be socially productive, is conceived as healthy, wealthy enough

and probably happy. Underlying these comments is the historical legacy of quality of life as a measure of the productive and socially acceptable body. It is the legacy of the measure of the value of life (Koch 2000), as estimated in an economically driven Western society. This is also echoed in the comment of a participant to the focus group:

All I want to do is improve the quality of my life. I don't need anyone to help me. I just want to help myself. I've got little ones to bring up on my own so I need to look after myself so I can look after them (Julie).

Here, quality of life is presented as a means to an end and the implication is the dialectical relationship between the possibility to fulfil one's role as a mother and one's quality of life. According to this, quality of life does not exist in a causal relationship to engagement in social activities, but rather interpenetrates it. In keeping the body as fit as possible, health care services provide it with the tools to exist beside its MS-isation. Whilst implicitly recognising the use of health services in enabling her to fulfil her social role, Julie disenfranchises herself from services as 'help'. She needs technical support and not empathy to enhance the capacity of her dysfunctional body. She does not want to be understood, or morally supported, but she needs and wants her body maintained at an optimal level of functioning. She needs and wants the MS-ised body to be one of her life territories, so that she can develop a BwO to escape from her territorialisation as a malfunctioning body.

The following extract is that of an interview with Ron, who has had to stop working a year before the interview because of the pain and fatigue caused by MS. His level of impairment can be positioned between that of Peter and Stuart on one side and of Jim and Julie on the other. Questioned about the increase in SEIQoL score between my first and second visit (from 67 to 87), he talks about acceptance:

- Ron: I've just accepted it... I just do as much as I can and that's it.
- M: Do you feel you've accepted it more than last time then?
- Ron: Well yeah. As time goes on more and more yeah.

In this case it seems that if there has been quality of life improvement (Ron does not think so, and does not identify with his SEIQoL scores), it is linked to the time he has lived with the disease rather than resulting from health service input. Ron talks about acceptance, but also about his acceptance that health services may not be able to,

after all, mend his body. In between our two encounters, he might have developed a BwO, in a way that enables him to see life beyond his MS-ised body in a more positive light. Time has enabled him to deterritorialise himself and to live his life in an impaired body.

This is an extract of the field notes taken shortly after my first encounter with Peter:

He places a lot of importance on his family and comes across as a very happy, cheery person. In spite of his severe impairments, he seemed in control of his health and his life.

For his first quality of life evaluation, Peter nominated as the five areas that were most important to his quality of life his relationship with his wife and his family, his eyesight, his wheelchair (for what it enables him to do), and reading. When I met him for the second time, he elected again his wife and children, self-motivation, sight, hearing and his ability to laugh as the five most important areas in his life. The time he has spent with his symptoms has enabled him to remain in control of the conceptual space of his quality of life by choosing its focus. His overall quality of life scores were 85 and 99 on those two occasions, respectively. I asked him whether these figures reflected in any way how he felt about his life. His answer is a sign of resistance to the academic and medical discourses that I, as a researcher, and the physiotherapist, as the provider of a 'patient centered' service, represent. "I told you I like life! One hundred and ten percent!... I'm floating!" Peter resists both the power of the health services and that of the evaluation, by implying that his quality of life might be measured or institutionalised, but only he can be responsible for the way he feels about his life. He resists the quality of life territorialisation that I try to impose on him. Later in the interview, he apologises for not responding positively to my question on the ability of health services to improve people's quality of life: "I'm sorry to spoil things!" In doing so, he resists the patronising tendency of services wanting to 'fix' people's life as a whole. In his view, not only can health services not impact on the quality of someone's life as a whole, but neither should they try: the aim of health services is to alleviate physical suffering, in a mechanistic way. He explains his thought:

No group of people, no foundation can come to you and say 'OK, you are happy' ... Life is for living and enjoying. I've got aches and pains

and troubles, just getting up and walking around, so what, moaning about them won't cure nothing.

For Peter, quality of life is a site of resistance to dominant medical and academic discourses, which takes the form of a rejection of quality of life as a measurable and quantifiable notion. Peter uses the medical discourse to show that only his frame of mind is important in making him happy: this translates in him choosing “self-motivation” and his ability to “laugh, look at myself and laugh” as two of the five most important areas contributing to his quality of life. I, in wanting and insisting to measure his quality of life and find ways in which health services could impact on it, place myself in a socio-critical paradigm that fails to account for his case. His MS-ised body does not exist in a vacuum, but rather in a dialectical relationship with his social environment, on which the services have little bearing and which a quality of life measurement cannot grasp.

### **c. Mind or Body**

Peter uses the medical discourse, with its Cartesian basis of mind / body separation (Descartes 1979), as a form of resistance to it. From this perspective, health services may alter the body-machine, but can do nothing about the person's quality of life. “It's coming from inside, not outside” (Peter). This comment rests on the assumption that ‘inside’ and ‘outside’ are opposed constructs. Yet the way people feel on the inside is inevitably influenced by what is happening around them and the only outside they can speak of is the one they perceive through their subjectivity. Peter bases his argument about quality of life on the dichotomy between inside and outside and illustrates repeatedly how he resists medical power. However, in order to be able to describe himself as a happy person, he relies on his *state of mind* and in doing so reproduces the Cartesian model of a mind / body opposition on which the medical discourse is based. So at the margin of his story is that of a patient who fits the biomedical model of healthcare but challenges the current national policies around patient centredness and holistic models of care. He places the locus of his selfhood in his mind and not in the body that is the focus of the service offered by the physiotherapist. Inside and outside cannot be as oppositionally situated as one may

pre-suppose, but are rather placed on a -sometimes discontinued- continuum which creates the conditions of one's environment and the way one feels about them. As exposed earlier in this work, the BwO is the field that enables this dialectical relationship between an unconscious and its environment. It follows from this that Peter has developed a strong BwO, which enables him to fully engage in deterritorialisation and live both beside and in his MS-ised body. He engages equally with the texts of the health services, in acknowledging and accepting their inability to cure his condition and with that of his own subjectivity, which places his senses and his family at the centre of his life. This ability to forge intertextual links enables him to see his physical condition with fatalism and to situate the quality of his life in what he remains in control of. He describes himself as happy, not only in spite of, but with his restricted health and mobility.

The time spent in contact with health services has led Peter, Ron and Julie to dissociate themselves from their patient position and present their self as a coherent whole, inside a body over which they have very little control. The long-term nature of MS and the length of time people spend in contact with the health services enables them to self-realise beside their bodily limitations and to engage with life differently.

#### **d. Space, time and the health services**

Every step in the happenings of a body takes time and leaves families to hope for something else.

In a way some days I get highly frustrated... I would like to see things move a little bit faster... Maybe I am looking for a cure... Like everybody is. I think that is what it is... It's frustration! You have really got to get to grips with this thing you know. We have got to get on with it as best we can... I am hungry for information all of the time you know... If there is something new, something better... I want to know about it (Moir).

The time that passes is the family's worst enemy as well as the source of their hopes since as the body deteriorates, the chance of scientists finding a cure increases. Time enables Moira to learn about possible cures, or new ways to alleviate Stuart's symptoms. Time is also an enemy, because it is what makes it difficult to get to

grips with this disease that leaves in the body the traces of what it used to be able to do. Through the body, time appears oppressive, measuring and controlling of people's activities. Medicine here is related to the notion of time, in that it makes life difficult by not 'curing' Stuart, but at the same time it is the only source of a hypothetical future solution. Through his body, time is oppressive, measuring and controlling of their activities. The time that passes leaves in their lives the traces of a 'properly' functioning body and forecasts the uncertain future the MS-ised body will face. Following surgical procedure, tremors are quite strong and Stuart cannot operate the wheelchair that would give him more mobility and enable the changes in position needed to ease his pressure sores.

It is just that we have got to wait for one thing and wait for another really, you know. We can't do everything at once. It is a waiting game... But I am constantly on to it. And I just want to see this now with the stitches out... The pain will subside and it's all finished with that now. Then we'll look at the wheelchair (Moira).

The difference between medicine and physiotherapy seemed to lie in their relation with time. While doctors are described as "busy...far too busy" (Moira), the physiotherapist's presence enables him to develop a relationship with his patients, and to know the MS-ised body as the subject of his treatment:

The physio... is all-important I think... This problem [MS] is a constant thing really. [Tim] can see changes better from worse. He's monitoring us... He will be taking notice every time he comes...what is getting better, or if there is anything worse... he knows it (Moira).

The physiotherapist is able to respond to expressed needs by his frequent presence. At the same time, he represents an integral part of the MS-isation process, leaving people to wait for his next point of contact. Physiotherapy, in contrast to medicine, is not seen as the source of a cure, but as what makes day-to-day living more bearable. Tim is closer to the couple than a medical consultant, who would only see them once every six months, but his work does not come without time constraints:

Obviously someone has only allocated a certain amount of time for us and everyone else... It would be nice just to ring someone up sometimes and you know...can you come out and look at this? (Moira)

The time Tim spends with the couple is perceived like a given, that enables Moira to learn how to manage Stuart's MS. Nothing can be done, but what Tim, who has to share his time between them and others, instructs them to do. Tim's time is not only

shared by order of urgency, or by the importance of the concern, but in an ordered and fair manner between all his patients. They have to fit in his and all other professionals' timetables, which have been designed to maximise efficiency. Tim's accountancy of his time in his quarterly reports is an illustration of this:

15 days annual leave, 13.5 days sick leave, 8.5 days study leave, and 88 days worked; in those 46% of the time was spent in direct patient contact time (activity report, March-May 2003).

Working in a rural area, and aiming to offer the flexibility to visit people at home meant that he could not create as much direct patient contact time as he would have liked. So in that sense, time is taken away from participants, when it is not their turn to be seen, or when they have to fit their needs in a pre-arranged schedule. Time is given and time is taken from the patients, while they find themselves in a 'waiting game', waiting for time to develop a 'cure' to make the body better, but also waiting for an inescapable bodily decline. So in keeping in close contact with his patients, Tim reinforces their territorialisation as MS patients, helping them to live with their MS-ised body. So Stuart's body is at the core of the couple's life, but it is the notion of time that is controlling what happens to it, either through the natural progression of the disease, or through the intervention of different health professionals. Through the medium of time, Stuart's body is the site of interplay between medical, professional and personal texts.

The notion of location and regularity of treatment is central to some participant's description of the service. Location can for example change the relevance of a treatment course: "going to hospital and (Tim) was saying, 'Now how can you do that at home?' And we figured that actually standing by the sink was the best place to do it" (Tom, focus group participant). The context of the home for this person brings meaningfulness to prescribed exercises. Accessing physiotherapy from home can make a big difference to people who experience mobility problems:

[before the service existed] We would go from here and in to the car, out of the car...in to the hospital, out of the hospital...in to the car... He was absolutely exhausted prior to getting any physio. Whereas now... The physiotherapist comes to the house and I mean he is... he has had a rest (Moir).

So while the service developers consider metered, physical space, it is the relative space of the possibilities of the body that matters to people. The area's geographical spread was deemed to result in some people, those living in the most geographically isolated areas, not having access to the same range of health services. However, some of the participants' isolation prior to the service was a result of a lack of contact with health services, whilst they lived in an *urban* area. Their case, then, questions the availability of health services not by geographical area, but by expression of need. Whilst some are living near a hospital, even that short journey puts too much demand on the body for it to benefit from physiotherapy sessions held there.

The following is an illustration of how time spent in hospital, in the short term at least, can be detrimental to a whole family's quality of life. Stuart's stay in secondary care resulted in some muscle wastage in his body, which he and Moira experienced as a step back from his progress prior to admission.

Moira: You see, I ... The only thing we do really is go along the caravan. That's what we do. We put [him in the campervan] which we've had modified... When he is in the wheelchair I put him onto a hydraulic lift...up...through the door... But all that is just no good if I can't transfer [Stuart] ... Turn him around and sit down; that is all it needs... That's all we need. Nothing else!... That is our only pleasure. And that is a couple of times a year. Apart from that, we sit in the garden.

ML: So really that, just standing up and going in a wheelchair, is just so key to your quality of life isn't it?

Moira: Absolutely! I mean I can hoist him in here, but I can't hoist him outside you know. And it is so important just... deal with the pain in his back...when he is trying to get up. He lost all that [when he was in hospital] a little bit of [immobility] and that.

In the institution, there was a body, with a need for electrical stimulation in precise areas of the brain in order to control involuntary movements. However, the time spent in the institution has shrunk the space occupied by the body, by limiting its ability to move. At the centre of this story lie the tensions between the aims of the medical profession, to stop tremors so that the patient can gain some degree of independence, and those of the family. The physiotherapy service lies in between these two, in providing the family with a link to 'busy' doctors and with the means of



managing the MS-ised body on a day-to-day basis. At the same time, Tim works within a functionalist paradigm, which, because of his close relationships with patients, invades other potential territories. If the body is MS-ised by the medical discourse, Tim's practice reinforces this territory and re-affirms its boundaries at each visit.

Participants express their wish to go on a short-term holiday, where space is displaced, away from the regimentation of their daily, normal lives. Time is spent away from the routines of the home, which may include visits from a number of carers, and the caravan gives them the space and the time to regain some control over their lives and share moments intimately and meaningfully. The time that passes enables people to disenfranchise themselves from the codifying practices of the health services, and to value the fluid and fleeting happenings of their life in their own right. This deterritorialisation can only happen when the body is displaced, away from the home and its caring routines.

The way in which the self is perceived is historically and culturally contingent. Participants, with their malfunctioning bodies, live in a semi-rural area of England, where health, and other, services are said to be sparse. In that particular sub-culture, people may be grateful for any services they can access from home. The body is at the core of both the family and medicine's focus, but it is on the level of functioning that their views differ. The body is seen by the medical corpus as lying at the core of one's sense of personhood and, as such, someone is deemed to suffer more from an inability to feed and dress oneself, rather than from the inability to go on a short-term holiday. From the family's perspective, the body is decentred to become what lies at the core of all family members' lives and what either enables, or prevents, them from doing the things that matter to them. The medical discourse on the other hand, sees the body from an individualistic perspective, in which one ought to be able to look after oneself, as much as possible. The territory of the MS-ised body is therefore a functionalist and individual one, which prevents people from developing Bodies without Organs and explore alternative territories.

**e. The service as surveillance**

The clinical gaze of the physiotherapist coming to people's home is a source of reassurance and breaks the isolation some people felt previously. "We don't feel isolated like we used to... You have been diagnosed and that is it" (Moirira). This isolation is not quite the same as the one serving as an argument for the service development, which highlights the mostly rural nature of the area. It rather refers to a lack of monitoring and surveillance after diagnosis. People are given a label of MS, but then not told what to do about it; at that time, the boundaries of the MS-ised body are physiological only. They lie in a diagnostic, which disempowers the people put in this new territory, because it puts them in a biological paradigm over which they have no control. Although it reinforces the boundaries of the MS-ised body, the physiotherapist's visits break this isolation. Physiotherapy clearly brings control and power to the relationship, as family members describe how they are instructed to do things.

When he comes here, he instructs me...because it is going to be a week again before he comes back... you know. He will tell me to do this and do that until he gets back again you know... Until [Tim] came... I was doing it wrong (Moirira).

Tim leaves instructions and corrects malpractices, he sees the need to "regularly remind people of what they ought to be doing." Some participants spoke like good pupils, who have learnt how to do things and are now able to apply their knowledge and do things 'properly'. The physiotherapy practice enables them to explore the territory of their MS-ised body. This activity of learning, which is contingent on the regularity and the frequency of the physiotherapist's visits, is empowering, in that it enables family members to care for their relative and, for example, ease stiff limbs. Implied by the words of some family members is the powerlessness and uncertainty that the disease progression injects in their lives. They feel powerless to do anything with the body, other than what Tim, who has to share his time between them and others, instructs them to do.

**f. The MS-ised body as a new territory**

In this rural area, there is a paradox between the concept of remoteness that underpins the service development and that mentioned by the service users. While isolation is mentioned by some study participants, it is not geographically based, but based on a lack of access to suitable health services. Peter demonstrates that a restricted mobility does not necessarily result in a poor quality of life and that the latter comes from 'the inside'. Although the opposition between inside and outside spaces can be disputed, three other participants imply it. These suggest that while people are minimally impaired and able to perform what is commonly perceived as valued social roles, quality of life may be determined by the extent to which these roles are fulfilled. People engage with the territories they know and when their body becomes MS-ised by diagnosis, they face the challenge of exploring this new territory. The physiotherapist service supports them in doing this, by helping them to read this new text.

The time spent with the disease seems to affect how oppositionally situated 'inside' and 'outside' are perceived to be, as one starts to be less concerned about external standards on how one should live one's life and more aware of internal resources for happiness (Corbin 2003). So, people can realise their happiness through their state of mind, quite independently from their bodily tribulations. But this is not to deny people's impairments and their struggles with their own physicality. To conceptualise these notions of the mind, the body and the MS-ised body as territories between which the BwO can travel, helps to understand why people with severely impaired bodies may, after all, think of themselves as having a good quality of life.

## Health and Disease

Health is often taken as a key construct that is necessary, though not always sufficient, to ensure a good quality of life. It is also understood through disease as its opposite (Gadamer 1996). On the other hand, people may carry a diagnosis of diabetes, for example, but feel perfectly healthy; or on the contrary many people feel unwell for some time without any formal diagnosis. The text of the healthy and that of the diseased are not distinct, but result from discourses generated by health care institutions and professions. Therefore, as such, 'health' and 'disease' have no essential reality. They may present an individual reality, by being anchored in an experiential body, but they do not exist beyond the cellular or molecular frames created by scientists. Fox and Ward (2006) conceptualise health as situational, relational, cultural and individual, and therefore not restricted by diagnostic specificities.

Health in our consumer culture is commodified, promoted, nurtured and often assimilated with beauty (Featherstone 2001; Lawton 2003). 'Body maintenance' as a movement to promote beauty and conserve youth and health, is an example of discourse that frames our experience and perception of health and illness. It has become central to a contemporary Western culture in which we tend to disregard the possibility of death (Lupton et al. 1995). Featherstone (2001) gives the example of the way in which Helena Rubinstein made her fortune through positing the formula equating youth with beauty and health. Barilan (2005) builds on this and describes a growing faith in the "pristine wholesomeness" (2005: 199) of the human body. He asserts:

In modern high culture... the story of the body and the story of the person are kept separate. Efforts are often exerted to keep the body in line whenever it deviates from an ideal of wholesomeness, youth and beauty (2005: 200).

Health promotion specialists, who assert that individuals who conserve their bodies through dietary care and exercise will enjoy greater health and live longer, build on this cultural trend. Television programmes that adopt a Look-After-Yourself approach (Karpf 1988) present an example of this. The health promotion movement attempts to bring about change, so that individuals assume increasing responsibility for their health, body shape and appearance. While this cultural trend does not foster acceptance of those who look different from the

celebrated Hollywood body shape, health promoters would argue that it nevertheless brings with it healthier behaviours. Featherstone (2001) argues that

However much health educationalists appeal to the rationality of self-preservation and offer the incentives of longevity and lowered risk of disease, their body maintenance messages are strongly influenced by the consumer culture idealisation of youth and the body beautiful (2001: 232).

He further describes the 'looking good feeling great' health education message as a "saleable commodity" (2001: 232). This is exemplified in the television programme *You Are What You Eat*, when at the beginning people are invariably presented in black and white, wearing unflattering swimming costumes in a rigid posture. After abiding, always reluctantly at first and then enthusiastically with the diet prescribed, they appear in full colour, thinner, in flattering clothing and make up, dancing and holding now oversized clothing items. Their transformation is complete as they go from looking miserable, unattractive and unhealthy to being portrayed as beautiful, happy and much healthier. Participants invariably describe their quality of life as tremendously improved as a result of this. So popular media not only equate youth, health and beauty, but foster an image of health = beauty = a life of quality. Health is sold as a commodity that extends life and improves its quality. The underlying assumptions of this movement are that the unhealthy body that is at risk of future diseases is unhappy.

In concordance with this, Beckman (2005) asserts that diseased bodies

are considered, and perceived as, 'uncivilised bodies', which show the external signs of a management gone wrong and therefore are interpreted as internal failures of the agent (2005: 207).

The body is a site of inscription on which ability and independence serve as positive markers of normality (Beckman 2005). Partly in relation to the degree of dependence it engenders, Frank (1998) compares being ill to being relegated to some "moral limbo" that can be challenged through individual stories. Beckman highlights that constructions of disability assume that there are absolutes of 'ability' and that: "every 'body' can only be really understood as 'temporarily abled'" (2005: 222).

The medical model has gained authority through its claim of moral neutrality (Kimsma and Van Leeuwen 2005), and produces a discourse in which healthy lifestyles are associated with positive self-identity (Williams 2000; Clarke et al. 2006). Through this model, patients are both responsible for their disease, and victims in need of care (Fox 1993). Critics of this

medicalisation movement, such as Zola (1973), saw it more as an expropriation of the health of individuals. According to this critique, diseases become social constructs and, as Kimsma and Van Leeuwen assert: “life is a series of medical phases with medically defined threats and therapies” (2005: 561). People are not guilty of their needs, as long as they follow the medical advice as compliant patients. Kimsma and Van Leeuwen (2005) describe how, in the seventies, demedicalisation became the focus of political and social battles in Western societies:

The dominant model became the somato-psycho-social model, explaining complaints and disease in terms of physical, mental, and social causes, at an individual level, to be handled by physicians, social workers, psychologists, nurses, and physical therapists (2005: 561).

The medical discourse has gained considerable power in history. However, according to Kimsma and Van Leeuwen (2005), the body is the site of battles between three dominant discourses. Medicine, with law and religion, remains at the root of civilisation and, as such, exerts a powerful influence on cultural values and values of selfhood. Kimsma and Van Leeuwen (2005) show how the discursive structures of religion are echoed in those of medicine, law and economics:

Table 1: Discursive structures of religion, law, economics and medicine, Kimsma and Van Leeuwen (2005: 567).

Discourse	Subject	Equilibrium	Deviance	Restoration
Religion	Sinner	Paradise	Sin	Confession
Law	Accused	Justice	Crime	Punishment
<b>Medicine</b>	<b>Patient</b>	<b>Health</b>	<b>Disease</b>	<b>Therapy</b>
Economics	Consumer	Wealth	Scarcity	Consumption

Following this analogy, the dream of a life without disease was formed as a secular paradise and hospitals came to replace churches as institutions representative of Western societies. A good quality of life is obtained in the equilibrium state of paradise, justice, health and wealth.

This discourse of the ‘abnormal’ that needs to be removed from the body leads to a radical disembodiment of the person, as well as a depersonalisation of the anatomical body (Barilan

2005). 'Dis-order' as a term, highlights our liking of what we are socialised to think of as 'ordered' and organised. This is a typical reflection of what Deleuze and Guattari termed the striation of our lives. Yet the dis-order is classified and understood in order to be, as much as possible and in a climate of ethical debates, eliminated. Eugenics is the ultimate and rational rejection of dis-order and celebration of Deleuze and Guattari's striated, state space through a science that reproduces itself. Life is territorialized in this ordered paradigm that rejects anything out of the order. Petersen and Lupton (1996) describe and critique the 'healthist' tendency of public health in postmodern times, based on the assumption that everyone should work and live to maximise their health. They assert that regimes of health and fitness

provide the occasion for policing the boundaries between the normal ('healthy') self and abnormal ('unhealthy') others... who are imagined as embodying all the properties falling outside the health - signified self (1996: 25).

Clarke et al. reinforce this: "In the biomedicalisation era, the focus is no longer on illness, disability, and disease as matters of fate, but on health as a matter on-going moral self-transformation" (2006: 172). However, disability activists for example, offer a territorialisation that can be just as strong and potentially oppressive, if different (Shakespeare 2005). People with long-term conditions are the focus of discourses emerging out of both the healthist and disability movement. Both of those assume that certain strict and universally applicable conditions are to be fulfilled before someone can have a good quality of life.

Following Deleuze and Guattari, the organism is a mere effect, exemplified in the modern period through the medical discourse. From this decentred self, Fox and Ward (2006) assert: "health must be acknowledged to be a highly contextualised outcome of the body/self and its relations with its material and psychosocial environments" (2006: 476). In other words, discourses of health and illness within the medical and human sciences, contribute to a particular territorialisation of the diseased BwO, organised as a biomedical or biopsychosocial body with organs. The modernist focus on disease serves to fabricate a subject who is effectively trapped within her malfunctioning body and who has to adjust to the limitations this engenders (Williams 2000). In postmodernism, the focus has shifted to a control and transformation of that body, in ways that promote self governance, surveillance and risk avoidance (Rose 2001; Clarke et al. 2006). The timing and context of, norms and expectations of and our commitment to events, are all crucial to the experience of our lives, healthy or sick (Williams 2000). At the same time, the relevance of body limitations and

activity restrictions should not be undermined, and Williams (2000) argues that “new paradigms must ... acknowledge the ‘fluidity’ of the world” (2000: 56). Williams (2000) further asserts that bodies and selves are continuously problematised through idealised images of consumer culture and the ubiquitous projects of body-maintenance, self-improvement and risk-avoidance that they engender.

The emphasis on testing and screening in order to diagnose, exemplified in current policy documentation (DoH 2005), is a manifest response to the threat of disease and death that lurks invisibly within the body (Clarke et al. 2006). Lupton (2001) asserts that the discourses associated with diagnostic test present it as “value-free determinations of a reality uncontaminated by social processes” (2001: 151). Anxiety about, for example, breast or cervical cancer, is deliberately used in health promotion campaigns to exhort people to attend screening and diagnostic tests. Symptomless people are forced to consider the possibility of harbouring a serious disease. Such exhortations often imply that not to attend such screening programmes is to let one’s own body as well as society, down, for having let cancerous cells spread unchecked. Lupton asserts:

Healthy women are exhorted to attend mammographic screening programmes ... only to be faced with a diagnosis which changes their lives but does not necessarily ameliorate their state of health (2001: 152).

With the advent of such screening programmes, disease is contained, and increasingly colonises, health. The boundaries between health and illness are blurred as health educationalists encourage us to live a life that will prevent the many diseases lurking within our bodies from developing, or at least to delay this development for as long as possible. Health is pathologised, regulated and screened for the avoidance of disease, and the diseased body is monitored closely to prevent or pre-empt future mis-happenings (Clarke et al. 2006). However, a paradox emerges, in that health is both increasingly biomedicalised through such processes as screening or surveillance, and less medicalised in that the onus for health shifts from the professional to the individual patient/ consumer (Clarke et al. 2006).



## **Re-presentation of long-term conditions in popular television**

### **a. The data**

Out of 529 programmes broadcast over the month of July 2005 in the time period included, 43 (8.0%) were explicitly health related. Two programmes were cancelled at the last minute; one without explanation, the other, less than a week after the London tube bombings, was replaced by a documentary on Al'Qaeda. 25 (58%) of the programmes included were fictional and 16 (37%) were documentaries, relating either to health / disease, to health care professions, settings or procedures, or promoting health. Karpf (1988) identifies four different types of health programmes on television:

- the medical approach, which celebrates medicine's curative powers;
- the consumer approach, which criticises the doctor – patient relationship;
- the look-after-yourself approach, which appeals for individual behavioural changes;
- the environmental approach, stressing the social origins of illness.

Table 2 provides a broad description of the programmes included, using Karpf's (1988) classification. Over the 43 features, the medical approach was used in 31 instances (72%). 7% adopted a consumer approach; 14% adopted the look-after-yourself approach; while 7% adopted an environmental approach.

Table 2: Broad description of all the programmes included in the analysis, per category

Name of programme	Dates and times	Channel	Setting	Description
<b>THE MEDICAL APPROACH</b>				
Scrubs	1 <sup>st</sup> , 8 <sup>th</sup> , 15 <sup>th</sup> , and 22 <sup>nd</sup> July, 20:00	C4	Hospital	Sitcom/ Life of health professionals; medical interventions
Nip/Tuck	6 <sup>th</sup> , 13 <sup>th</sup> , 20 <sup>th</sup> and 27 <sup>th</sup> July, 22:50	C4	Private clinic	Drama/ Life of two surgeons, families and staff; Plastic surgery
Casualty	2 <sup>nd</sup> , 9 <sup>th</sup> , 16 <sup>th</sup> , 23 <sup>rd</sup> , 30 <sup>th</sup> July, 20:20	BBC1	Hospital	Drama/ medical and surgical interventions, generally in emergency situations.
Holby City	5 <sup>th</sup> , 12 <sup>th</sup> , 19 <sup>th</sup> , 26 <sup>th</sup> July, 20:00	BBC1	Hospital	Drama/ Hospital politics, medical and surgical interventions
House	7 <sup>th</sup> , 14 <sup>th</sup> , 21 <sup>st</sup> and 28 <sup>th</sup> July, 22:00	Five	Hospital	Drama/ medical detective work
Where The Heart Is	3 <sup>rd</sup> , 10 <sup>th</sup> , 17 <sup>th</sup> , 24 <sup>th</sup> and 31 <sup>st</sup> July, 20:00	ITV1	Community, Yorkshire	Life and work of community nurses and their families
The Private Life of Harley Street	11 <sup>th</sup> , 18 <sup>th</sup> , and 25 <sup>th</sup> July, 20:00	BBC2	London, Harley Street	Documentaries following the treatment of patients in private settings. Includes interviews of practitioners and patients. Issues of halitosis, gall bladder, reconstructive breast surgery, digestive or respiratory problems as well as deafness, artificial insemination or alternative therapies, were covered.
Trauma	21 <sup>st</sup> and 28 <sup>th</sup> July, 21:00	BBC1	London / Africa	Follows health care professionals as they get to trauma scenes, and take injured people to hospital. People's hand over and treatment in hospital is then followed. One of the episodes followed the rescue teams after the London tube bombings of the 7 <sup>th</sup> July.
Your Life in Their Hands	27 <sup>th</sup> July, 21:00	BBC1	Hospital	On epilepsy and the dilemmas faced by parents when the only real option open to their child is a potentially life threatening brain surgery. Included interviews of neuro-surgeons (worried about "going from hero to zero") as well as patients and families.

**CONSUMER APPROACH**

Panorama	13 <sup>th</sup> July, 19:00	BBC1	Birmingham	Undercover Hospital Clinic: an undercover cleaner shows the lack of adherence to basic hygiene and cleanliness procedures in a hospital with Foundation Status
Panorama Special	20 <sup>th</sup> July, 21:00	BBC1	Hospital	Undercover Nurse. A nurse undercover describes the poor standard of care given to older people in several hospital wards. She also describes the problems faced by the ward manager.
Dispatches: <i>On Pain of Death</i>	18 <sup>th</sup> July, 20:00	C4	N/A	Showed how health professionals are often reluctant to deal with dying patients, and lack training to do so. As a result, people die in pain, even when they are in hospital. There are inequities in provision of palliative care across the country. 75% of people die due to non-cancer conditions, yet 98% of hospice patients have cancer.

**LOOK AFTER YOURSELF APPROACH**

You Are What you Eat	13 <sup>th</sup> , 20 <sup>th</sup> , and 20 <sup>th</sup> July, 20:30	C4	Participants' home	Change of diet for overweight people
Should I worry about...?	14 <sup>th</sup> , 21 <sup>st</sup> 28 <sup>th</sup> July 19:00	BBC1	N/A	Short synthesising documentaries about various health related topics, such as additives in food, exercise and cancer.

**ENVIRONMENTAL APPROACH**

Victoria Wood's Big Fat Documentary	21 <sup>st</sup> July, 22:35	BBC1	N/A	Documentary looking at the cultural, industrial, as well as health, aspects of dieting.
Tonight with Trevor McDonald	29 <sup>th</sup> July, 20:00	C 4	N/A	Covers topical issues – this feature was on the social and health consequences of binge drinking.
This World: <i>Bad Medicine</i>	12 <sup>th</sup> July, 21:00	BBC2	Nigeria / Britain / India	Documentary about fake drugs flooding the markets in Nigeria. It is a dangerous but lucrative trade that has led to outbreaks of drug resistant strains of malaria, tuberculosis and HIV. A lot of these drugs are manufactured in India. Some, particularly tranquillisers, can be found in the UK too.

**b. The four categories of programmes**

Although the technique of content analysis is in itself fairly simple, it requires a level of interpretation that has to be acknowledged at the outset of the analysis (Stokes 2003). The categories cited below were born out of my immersion in this data and are therefore subjective. Also, there could be a level of uncertainty about where to classify some of the terms. For example, depending on the context of the programme, the word 'risk' could alternatively refer to a surgical procedure, a health promotion comment or to the implications of a lack of adherence to standards of hygiene in a hospital. The results are presented in this section, in percentage of the total number of health related terms counted.

***The medical approach***

Table 3 shows the frequency of words counted in each programme type, in percentage of the total number of words counted for the category.

Overall and not surprisingly, words describing medical conditions prevailed in this category of programmes. Medical professions, conditions, their symptoms, their treatment and death were the most frequently mentioned areas, together with traumatic events and surgical procedures. Death was frequently talked about, mostly in relation to traumatic events or risky surgical procedures.

While *Holby City* stands out for using the most medical jargon, *Nip/Tuck* included most words about life in general. This included consideration about the meaning of life and one's purpose in life. *Nip/Tuck*, *Scrubs* and *Where the Heart Is* are indeed as much about the lives of the professional protagonists as their work as health professionals, which is reflected in the low number of medical terms used. *Where the Heart Is* and *Your life in their hands* related the most experiential accounts of disease, while the first used the most health promoting terms.

Table 3: Percentage of words counted per category for each programme included in the medical approach.

%	Casualty	Holby city	House	Nip/Tuck	Scrubs	Where the heart is	Harley Street	Trauma	Your life	Frequency (in nb of words)
Care professions or specialties	11.3	26.7	14.4	5.8	12.7	15.1	0.0	8.9	5.1	292
Medical conditions or descriptions	6.9	26.1	30.1	7.8	0.8	6.6	11.1	1.2	9.4	605
Symptoms	12.6	19.7	25.2	10.6	2.0	8.3	0.4	9.1	12.2	254
Trauma	23.4	12.6	2.9	12.1	2.1	7.5	0.4	38.1	0.8	239
Surgery	2.1	30.6	0.0	3.4	10.6	8.5	24.7	0.0	20.0	235
Health care settings & organisation	5.2	40.5	6.5	2.0	3.9	4.6	3.9	28.1	5.2	153
Investigations and tests	10.6	53.1	15.0	3.5	8.0	0.0	0.9	0.9	8.0	113
Intervention or procedure	6.3	38.7	12.0	7.7	4.9	0.0	21.1	2.8	6.3	142
Body parts, fluids or signs / 'patient'	9.3	44.2	21.9	7.4	6.4	3.3	1.0	6.4	0.2	421
Drugs, treatments and side effects	0.0	21.4	59.3	3.6	5.0	4.3	0.0	6.4	0.0	140
Health promotion	0.0	36.8	5.3	0.0	15.8	31.6	10.5	0.0	0.0	19
Death	19.7	30.5	15.3	10.3	4.4	6.4	0.0	10.3	3.0	203
Life	5.7	13.2	11.3	28.3	0.0	7.5	7.5	11.3	15.1	53
Experiential accounts	0.0	0.0	0.0	0.0	0.0	46.7	0.0	0.0	53.3	15
Other	50.0	0.0	0.0	0.0	0.0	0.0	50.0	0.0	0.0	2

605 terms were counted as medical conditions in this category. Following the WHO (2002a) definition of long-term condition, 33% of the conditions counted in this category can be considered as long-term. This includes cancer, multiple sclerosis, auto-immune conditions, Addison disease, sarcoidosis, osteopenia and neurofibromatosis. It has to be noted that the last five of these terms were used in *House*, where every week Dr House and his team have to solve a medical mystery and discover what a patient suffers from in order to save him or her. The life of the patient involved is invariably in danger, until the medical team finds what their symptoms point to and treat them, always successfully. So the situations described in the episodes are invariably acute and long-term conditions are mentioned as possible solutions to a mystery. While cancer was mentioned in most programmes, multiple sclerosis was only used in *Holby City*, to describe a lady who was having a baby. She perceived the members of her family as being overprotective in insisting that she was going to need a lot of help with the baby because of her condition. The programme presented her as courageous and fighting for her independence. It ended well, as her mother-in-law backed off to let her look after the baby herself.

It is interesting to note that seven of the nine programmes included in this category take place in hospital settings. Only one, *Where The Heart Is*, is set up in the community. Whilst there might be an expectation that hospitals have to deal predominantly with acute situations, nurses working in the community play a role in the management of many long-term conditions. In the episodes of the drama included in this analysis, of the 40 conditions mentioned, 5 were of chronic. The most frequent mention, muscular dystrophy, was used in an episode where a mother was concerned that her son might have this condition. Whilst it turned out to be glue ear, it is interesting to note that the episode did not talk about life with muscular dystrophy, but rather fear of the possibility of the disease.

Epilepsy was frequently mentioned in an episode of *Your Life in Their Hands* dedicated to the condition and its treatment, through the removal of abnormal parts of the brain. In this programme, only very severe cases of epilepsy were shown, for which high risk brain surgery seemed the only option. The terms 'abnormality' and 'deficit' were used in *Your Life in Their Hands* to refer to dysfunctional parts of the

brain which cause seizures in epilepsy and the impairments that may derive from a brain operation.

### *The consumer approach*

Table 4: Percentage of words counted per category for each programme in the consumer approach.

%	Panorama	Dispatches	Frequency (in nb of words)
Care professions or specialties	46.7	53.3	60
Medical conditions or descriptions	17.0	83.0	100
Symptoms	56.8	43.2	88
Trauma	0.0	100.0	1
Surgery	0.0	0.0	0
Health care settings & organisation	28.5	71.5	123
Investigations and tests	0.0	100.0	1
Intervention or procedure	10.3	89.7	39
Body parts, fluids or signs / 'patient'	0.0	100.0	15
Drugs, treatments and side effects	55.2	44.8	29
Health promotion	0.0	0.0	0
Death	70.5	29.5	78
Life	0.0	100.0	1
Experiential accounts	17.6	82.4	17
Other	100.0	0.0	5

In this category of programme, words describing health care professions, settings and symptoms are most frequently used. *Dispatches* mostly talked about medical conditions, their treatment and the health care professionals needed to administer them. *Dispatches* 'On Pain of Death' used particularly powerful images of disease, pain and dying in the UK and took a critical stance in showing how death is often a neglected quantity in the NHS. *Dispatches* exposed NHS settings and described the pain in which some people die, even while in hospital. Health care professions and settings were therefore frequently mentioned, as were the symptoms that were left unrelieved and, as the core subject of the programme, death. Maybe surprisingly, the two *Panorama Undercover* programmes featured the most frequent use of words

relating to death. These related to the risks that older people face through lack of care. The two programmes also used words to relate people's untreated symptoms and lack of successful treatments.

These three programmes included a focus on infections and MRSA, which represented 60% of all the conditions mentioned. This was largely due to the two *Panorama* programmes. These contributed to the topical scare stories about the lack of safety of hospitals and, as such, were highly politicised. *Dispatches: On Pain of Death* talked about "long lasting chronic illnesses", and names of long-term conditions were made to float across the screen to illustrate the commentator's text, such as ischaemic heart disease, chronic obstructive pulmonary disease, or lung, trachea and bronchial cancer. The programme portrayed the majority of people in the 21<sup>st</sup> century as dying "slowly from chronic illness rather than suddenly from infection". The commentator contrasted this with medical professions' increasingly focused specialties, few of which including dying, and described how "doctors want to save people" and not to "let go". So dying is part of life with a chronic condition, but is not part of most medical professions' specialty and few professionals were portrayed to either recognise the dying phase or to adequately address pain and symptom control. Most of the long-term conditions mentioned were referred to in a descriptive sense, rather than relating to experiential aspects. This was used in a rather dramatic manner, in relation to people dying in pain.

### ***The Look after Yourself approach***

Not surprisingly, it was the health promotion discourse that was predominant in this category of programme. This could include terms such as 'fitness', 'exercising', 'fatty' or 'healthy' foods, 'vitamins', or 'minerals'. Most of these programmes focused on food and drink and in part their relation to health, except two episodes of *Should I Worry About*, which focussed on cancer and exercise.

Medical conditions came second in frequency on the list of word categories and were mostly used in *You Are What You Eat* and *Should I Worry About*, as examples of possible consequences of existing lifestyles. In comparison with the previous category of programme, medical conditions were mentioned less. Behavioural problems were mostly mentioned in the *Should I Worry About* on food additives and



their impact on children. Obesity was mentioned in both programmes. Cancer and diabetes were the two most commonly mentioned long-term conditions, as likely consequences of unhealthy lifestyles.

Table 5: Percentage of words counted per category for each Look after Yourself programme.

%	You Are What You Eat	Should I Worry About	Frequency (in nb of words)
Care professions or specialties	58.3	41.7	12
Medical conditions or descriptions	49.4	50.6	77
Symptoms	81.8	18.2	11
Trauma	0.0	100.0	3
Surgery	0.0	100.0	1
Health care settings & organisation	0.0	100.0	4
Investigations and tests	100.0	0.0	6
Intervention or procedure	0.0	0.0	0
Body parts, fluids or signs / 'patient'	31.3	68.8	48
Drugs, treatments and side effects	0.0	100.0	1
Health promotion	28.9	71.1	339
Death	0.0	100.0	6
Life	100.0	0.0	5

### ***The environmental approach***

*Victoria Wood's Big Fat Documentary* focused on the social and commercial aspects of dieting and their potential health impact. Similarly, the *Tonight with Trevor McDonald* episode focused on the social, as well as physical, consequences of binge drinking. The majority of *This World* took place in Nigeria and, thus, might not have had the same appeal to viewers, even if the programme ended by giving examples of fake drugs that can be found in the UK.

Table 6: Percentage of words counted per category for each ‘other’ programme.

%	V. Wood’s documentary	T with T. McDonald	This world	Frequency (in nb of words)
Care professions or specialties	0.0	23.8	76.2	21
Medical conditions or descriptions	47.6	26.2	26.2	42
Symptoms	0.0	93.3	6.7	15
Trauma	0.0	100.0	0.0	1
Surgery	0.0	16.7	83.3	6
Health care settings & organisation	9.1	9.1	81.8	11
Investigations and tests	0.0	11.1	88.9	9
Intervention or procedure	0.0	89.5	10.5	19
Body parts, fluids or signs / ‘patient’	16.3	0.0	83.7	92
Drugs, treatments and side effects	0.0	83.3	16.7	12
Health promotion	63.6	1.8	34.5	110
Experiential accounts			100	8
Other	100			23

Interestingly, this category of programme was dominated by the health promotion discourse, mirroring societal concerns for healthy lifestyles. The ‘other’ word category in *Victoria Wood’s Big Fat Documentary* mostly referred to the diet industry and the failure of most commercialised diets. In contrast with the other categories of programme, here fewer medical conditions were mentioned. In the *Trevor McDonald* programme on binge drinking, these related mostly to liver disease. The *Victoria Wood* documentary talked about compulsive behaviours towards food, anorexia, bulimia, obesity and diabetes. *This World* related to diseases mostly treated in developing countries, such as tuberculosis and to the health consequences of illegal medicine, such as multiple organ failure in extreme cases.

### c. Long-term conditions as a template yet to be reversed

Over the features included in this chapter, the medical approach was used in 72% of instances. In her book *Doctoring the Media*, Karpf (1988) describes the medical approach as being centred on diseases, which are perceived as disrupters of the

body's normal functioning; diseases are pathological, but they are also abnormal. The medical approach focuses on the cure of acute diseases, rather than the management of chronic degenerative conditions, and favours biological explanations that pathologise individual bodies. It emphasises sophisticated and technological care patterns, generally based in hospitals.

Of course, producers do not make television programmes to provide accurate information, but are rather led by an agenda of successful entertainment. Seale (2003) describes how the public has come to expect the traditional binary oppositions that form the bulk of health reporting in the media. Producers have to play on these expectations, to feed the public's appetite for novelty. Templates of created understandings, for example those of families living with a severely disabled child who depend on scientific advances for a betterment of their lives, only have a certain currency. When the topicality of a template starts to weaken, producers sometimes operate a 'template reversal', in order to maintain the viewers' interest and increase the entertainment value of their programme (Seale 2003). News stories that demonise doctors for engaging in euthanasia, for example, are part of a reversal of the template of the benevolent and life-saving doctor. In the sample included in this chapter, the *Panorama* programme on dying in pain in Britain functions on the same principle, in total reversal to the *Your Life in Their Hands* episode on epilepsy. Seale (2003) describes the meta-narrative that runs through the mass media as being composed of five key elements on which templates and reversal techniques are applied: "The dangers of modern life; villains and freaks; victimhood; professional heroes; lay heroes" (2003: 521).

Examples of these can be found in the analysis presented here. Villains and freaks threaten our sense of security in that they question our acceptance of health as a given (Seale 2003). *The Private Life of Harley Street* is replete with micro stories of freakishness that has to be modified, improved and, if possible, cured. Representations of sick children are the classical example of the victimhood underpinning of media meta-narrative of health in the media. The *Your Life in Their Hands* on epilepsy is one such example. All the programmes using a medical approach represented stories of health care heroes, while some of the look-after-yourself approach celebrated the successes of lay people in defeating temptation, for

example. The dangers of modern life as the first of Seale's themes, aims to feed into a risk-averse culture (Seale 2003). *Should I Worry About...* is the archetype of this category. The two *Panorama Special* programmes, as well as *Dispatches* and *This World*, are examples of this offering of alternative narrative viewpoints to create and feed fears of going to unhygienic hospitals, growing older, dying or taking fake medicines.

The expansion of public health messages is clear and pervades the data. Leichter (1997) talks about the organised focus of a new 'secular morality', in what he calls the 'wellness movement':

The text of the wellness movement has been that adopting more healthy lifestyles will lead to longer, healthier, and more enriching lives. There is however, a subtext to the movement that has little to do with health and a great deal to do with social status. It is this dimension to the wellness movement that has infused it with a sense of moralism, or more appropriately, moral posturing, that I have chosen to call lifestyle correctness (Leichter 1997: 371-372).

Such moralistic therapeutic discursive practices reflect contemporary society's obsession with lifestyle simulations. Life on television becomes tidier, nicer, healthier or thinner; it is hyperreal. We witness our lives being potentially transformed from unhealthy and chaotic to healthy and orderly – see for example the 'before' and 'after' of *DIY SOS*, *Super Nanny*, *You are What you Eat* and many other programmes. King and Watson (2005) argue that this surge in lifestyle programming is a

fairly recent obsession [that] is an effect of late capitalist, postmodern societies to simulate order, combined with the powerful and often moralistic discourses of order, cleanliness and anti-infection characteristic of Western societies (2005: 229).

This is inscribed in what Clarke et al. (2006) have termed the 'biomedicalisation of life' in postmodern societies. In other words, quality of life in postmodern societies is territorialised by moralistic discourses of order and disease prevention. This approach assumes that health and illness are oppositionally situated within the body and that the first contributes to a good quality of life whereas the second is in itself enough to produce a bad quality of life. It is a story that fits acute, episodic models of disease, but that is at odds with the longitudinality and the incurable character of many long-term conditions. A good life on television is ordered, healthy and free of

vices such as gluttony or addictions. This manifests itself in an aesthetically pleasing body, which lives in a well designed and tidy environment. The data does not evidence any reversal of this template.

The programme that talked mostly about long-term conditions and quality of life focused on dying. Although the month of July might not have been representative of a whole year, this begs the question about the place left in popular culture to people who live with long-term conditions. Mass media stereotypes selectively feature and reinforce some of the available roles and images for people with chronic illnesses. These stereotypes of the vulnerable person who is ill and depends on state of the art medical intervention to regain some quality of life, or who dies in terrible pain, operate within the constraints of the audience's immediate environment. The majority of audiences are seen as healthy and stereotypes of long-term conditions reinforce a deeply ingrained fear of illness. Gross (2001), studying the representation of minorities in the media asserts: "we are all colonised by the majority culture" (2001: 414). Cheu (2002) echoes this in his study of the representation of disability in futuristic films. He establishes how disability is commodified as an 'otherness' that is undesirable, unless medical cure is possible. He states:

If impairment is an undesirable state of being, and being disabled an undesirable life, we can begin to understand the premium placed on medical cure, and the weight of the medical model in the eradication of disability in science fiction films (2002: 199).

As we have seen in this chapter, this remark can be extrapolated to long-term conditions in popular media: they are generally seen as detrimental to people's life and images of cure or death are portrayed, rather than images of life that may not be limited to an illness. The body with organs, which is mechanistically apprehended, dominates television stories of health and illness.

Overall, with the exception of one programme, long-term conditions were only mentioned sparsely. When epilepsy was mentioned in *Your Life in Their Hands*, it was mostly in relation to the difficulties of performing brain surgery. The programme only showed very severe cases of epilepsy and was as much about the surgeons as it was about the families' experiences. So when long-term conditions

appeared in artefacts, they did so in order to play a supportive role to the chosen narrative for the programme, which in the sample was curative medicine. Long-term conditions could thus be narrowly stereotyped, or, as Gross puts it, “symbolically annihilated” (2001: 409) through under-representation. Chronic diseases are not represented as such, but they are signified by stories of self-surpassing medicine. They are also re-presented in a temporal linearity, where they are signified as a risk to be avoided through the adoption of healthy lifestyles. The reasons for this can be speculated upon, but one of them may be the fact that they represent too big a contrast with the modernist icon of health as a norm and medicine as a self-surpassing curative enterprise. They may also lack the sensationalism required for popular television, even in the summer months, although they could be the focus of alternative template reversal. An obvious limitation of this study is the exclusion of serial dramas, where cases of diabetes, arthritis and Alzheimer’s are presented on occasions. Soaps present the ideal setting in which the longitudinality of living with a chronic condition could be represented, as people are familiar with the characters they see episode after episode. However, *Where the Heart Is* is one such series which was included, since it related the life and work of community nurses, yet included only the mention of fear of diagnosis with long-term conditions.

What then, could a positive representation of long-term conditions look like on national television? Representations of illness set the frame for what is considered normal, healthy or good in people’s life (Darke 1998). So when long-term conditions are represented as support to the narrative of a technological curative medical enterprise, they are implicitly contrasted with the undiagnosed, healthy looking body. If disability imagery is complex and if what authors count as positive or prejudiced representations vary (Darke 1998), the ‘proper’ rules of representation for long-term conditions are even more confusing. Representation as deviance from a healthy norm at risk of impairment derives from an unhelpful medical discourse. Paradoxically, any representation that highlights difference would potentially not promote acceptance of this difference, but rather reinforce our sense of what a healthy body should be able to do. So a positive representation of long-term conditions would first break this duality of the healthy or unhealthy body and show a fluctuation of able-body-ness in time and space. It would not negate the medical discourse in a complete template reversal, but rather place it within the context of

people's lives. Storylines of diagnosis are inevitably underpinned by a medical discourse, since it produces the diagnostic classification, but they also participate in fabricating an imagery of health, through what it is not.

In the light of the previous analysis, it seems reasonable to assert that popular culture instils and reinforces ingrained beliefs of illness as a finite interruption of a healthy life. Of course, that is not to say that everyone in Britain who might have watched some or all of the programmes included in this chapter subscribe to what Frank (1996) describes as a narrative of health restitution. We absorb media messages about health and illness and discount or modify them in complex, and often paradoxical, ways (Karpf 1988, Kellner and Durham 2001).

This chapter illustrates the fact that while the discourse of medicine is increasingly challenged in the media, it is superseded by health promoting and preserving discourses. The modernist dualistic assumptions questioned by postmodernists seem to remain unchallenged in television programming about health. The body remains territorialised in an organ-ised entity that can be approached in a moralistic, individual and mechanistic manner. The organ-ised body is experimented on, is left to suffer and die, or has to be kept within norms of health. Within this framework, quality of life is assimilated to health and the organ-isation of the body does not leave space for alternative narratives to be highlighted. This organ-isation is reflected in the creation of tidier, cleaner and better designed living environments. The organ-isation of the body is externalised to encompass an organisation of its immediate environment to improve its quality of life. In this sense, while this analysis is limited in terms of time, this chapter contributes to this thesis by providing an overview of how health and illness are approached and assimilated to quality of life in television programming.

## **Independence and Dependence**

As an adjective, independent is defined as

1) free from control in action, judgement etc.; autonomous. 2) Not dependent on anything else for function, validity, etc.; separate. 3) Not reliant on the support, especially financial support of others. 4) Capable of acting for oneself or on one's own (Collins English Dictionary 2003).

Someone who is independent is free from the influence, guidance, support or control of others and is self-reliant in physical and financial terms. Independence is a positive characteristic, oppositionally situated to dependence, which carries negative connotations. It can be synonymous with 'addiction' or 'neediness', for example. In health care, independence is often assumed to happen in the absence of pathological processes or with the expert guidance of professionals.

Through NHS policy documents (DoH 1998), people are 'educated' and 'empowered' to self-care and remain independent. However, there is little place in this framework for one to be able to choose exactly what one wishes to be independent in (Reindal 1999). An individual may, for example, choose independently to relinquish the care of his body and concentrate his energies on the things that matter most to him. One may be independent in one area of one's life, because one accepts a degree of dependence in another. For example, most of us relinquish the task of manufacturing our clothes to foreign factories, so that we can focus our lives on tasks more meaningful to us. The highly specialised division of labour in modern industrialised societies leaves us particularly vulnerable to all kinds of social changes. So complete independence rarely exists in Western societies and is always defined from a level of socially accepted dependence.

Foucault (1977) describes how objectifying technologies of control are provided, for example, by criminality, medicine and psychiatry. These are deployed within institutional settings in which the architecture reinforces the 'truth' of the objects they contain. Most people's homes have not been built purposely to accommodate impaired bodies, but health care practice alters their architecture by providing aids and adaptations. The new home care setting, with outward signs such as ramps, becomes a testament that instead of being a home, the building is now the house of someone with impairments. Aids and adaptations may improve independence,



but also objectify the person as some deficient body in need of health care expertise to function 'normally'. They enable a regulation of bodies in time and space, outside of the institution (Angus et al. 2005), and create a context in which the person is more easily totalised as her impairments. Angus et al. (2005) describe how aids and adaptations can alter people's homes in a disruptive and un-aesthetic way that sometimes causes distress. Also, while assistive technology may be made available to people with impairments, this may not always be usable in the context of their particular lives (Lutz and Bowers 2005). Lutz and Bowers (2005) also highlight that the presence of such technological apparatus can make it difficult for people to create or maintain relationships where their diagnosis is not central. Instead of only promoting independence, they therefore promote an image of the dependent body.

Fox (1999) provides an analysis of the ethics and politics of caring. He defines care as principally a relationship based on power and technical ability, which he calls the *vigil* of care, or care as discipline. In contrast to this, the *gift* of care is "mediated by generosity, love and celebrates difference" (Fox 1999: 78). In institutional settings, the two caring activities often co-exist. When a relationship of trust is established between a therapist and her patient, this can be empowering for the patient and enable her to break free from this dependence. However, when this caring becomes codified by professional discourses or settings, then the relationship becomes disempowering and fosters dependency (Fox 1999). In other words, the process of the professionalisation of care holds within it the possibility of a dependent relationship. This is because, through professionalism and theory, discourses are created, which fabricate the 'cared for' and create their market of dependent beings. So caring can be experienced both as liberating and as oppressive. It can both promote independence and convey in its existence the inscription of dependence of the subject. It derives from these reflections that when autonomy is supported either technologically or through a caring relationship, independence depends on a form of dependence for its very existence.

Independence is a valued characteristic in Western individualist societies. The misfit of the concept of dependency is evident in this context. However, we live in an era of globalisation, where true independence seldomly exists. We are all dependent on our environment and real independence is a fallacy of Western modernist and capitalist culture. This dependence, however, is not only accepted in society, but for example depending on others to produce our food is not seen as dependence at all. The terms of dependence and independence are

therefore interlinked and inter-dependent. This dichotomy of the dependent or independent subject is based on a modernist “dis-embodied” and “dis-embedded” notion of the subject (Reindal 1999: 359). In modernity, the subject is responsible for its own making, independently from its body or environment; it is essentialised. When one considers the postmodern subject as the result of constant dialectics between her unconscious and her environment, independence becomes inter-dependence. The BwO enables multiple deterritorialisations as the physical body and the social environment change. This inter-dependence is suppressed in medical and biological discourses, in favour of the simplistic dualism explored there. In contrast to this, Gibson (2006) offers a reconceptualisation of dependence as connectivity. In this framework, “selves are distributive, both confined to individual bodies and simultaneously connected, overlapping with other bodies, nature and machines” (2006: 189). This connectivity can be understood with Deleuze and Guattari’s (1980) BwO, since within this framework a body with organs is an organised entity of singular elements. These elements do not need to be of the same essence, and can therefore be biological or technological (Currier 2003). The organised body is therefore an assemblage of entities of different kinds that engage in connectivity to make a fluid whole function.

## **The ACTIVE programme**

### **a. The time-space and timeliness of the sessions**

The service was born out of the fact that most people listed on the local MS physiotherapy register presented with moderate or severe impairments. The physiotherapist, Lisa, developed this self-management and education programme aimed at people with minimal impairment, in the hope that it would enable people to retain a greater control over their body during the rest of their illness trajectory.

we often see people with moderate to severe impairment and by that time they've got their problems and you think, 'Well if I'd seen them five years ago and maybe explained 'If you do this it might stop that happening', then perhaps it might have prevented [some of it]' (Lisa).

The information sessions “assist the patients to reach their full potential in terms of quality of life, giving them and their carers the opportunity to develop a deeper understanding of their condition” (Lisa’s proposal to the MS Society).

The place in which the education and exercise sessions should be run was of great concern to Lisa. For the first round, the information sessions took place in a hotel, whereas they were located in the hospital physiotherapy department for the second round. In both cases, directed exercises took place in a local leisure centre. For some participants, going to a leisure centre could be quite daunting: “[in gyms] you see a lot of people who are very fit and very thin and very, you know, very athletic and [some participants] felt embarrassed, self conscious” (Lesley). Others found how misplaced their assumptions had been, which put them more at ease: “There were not really many six packs in there!” (Mark).

The timing of the sessions was also the subject of many discussions in the programme steering group. During the course, progress was monitored and remembered by the participants:

I went on the treadmill and one week I was walking fast which I can't do normally but because you are holding on, the balance isn't a problem and the last time I went on it, it was only a few seconds but I jogged (Jane).

Lisa had also developed self-evaluation sheets that enabled each participant to record their performance for each of the activities, week after week. This enabling of self-surveillance proved very popular among the participants. The time spent on the course had a physical impact and left an imprint in the body of some of the participants, in the form of improved performance.

Participants saw the timing of the programme in people's illness trajectory as an important factor:

Bear in mind we did it in the summer this year it's well over a year since I was diagnosed, it would have been better, I think for me, to have done it straight after... When you've got fresh questions and when you've got a lot of things you want answering (Michelle).

So to this person, the education part of the programme should have been made available straight after diagnosis. This goes against the widespread and maybe paternalistic assumption that people cannot take on too much information straight after diagnosis. However, the following person highlighted the importance of a different timing for the ACTIVE programme in individuals' particular MS journey.

I certainly think that for people that perhaps who are not freshly diagnosed, but that have been diagnosed maybe a couple of years. That [the programme] must... I could only see that benefiting their quality of life (Terry).

Irrespective of whether the programme should be made available to people straight after diagnosis, or a few years later, what these quotes highlight is the necessity to target people who are at a similar stage in their lived journey with MS. This is not determined by the physical time that passes, but is rather contingent on people's reading of their condition. The time spent with the condition must allow people to be open to receive the information delivered and engage in the exercises. This puts in question the inclusion criteria for the sessions, which were based on physical abilities solely:

Diagnosis of multiple sclerosis; Able to walk 100 meters without aid; Score of less than 6.0 on the Kurtzke Extended Disability Status Scale (Kurtzke 1983); -No known history of cardiovascular, respiratory, orthopaedic, metabolic, or other medical conditions that would preclude participation in the prescribed training programme (Lisa's proposal to the MS Society).

Rather than necessarily reflecting Lisa's beliefs and attitudes, these types of physical and measurable criteria were expected by the funding body. This, however, negated

her own personal knowledge of the people who, in some cases, she had been treating for years. What this highlights is the focus on people's physical state as the valued way to classify people, occasionally to the detriment of the intuitive knowledge of people themselves and the professionals who may know them well. It has to be noted that the MS Society, which is "governed by people affected by MS" (MSS 2005), funded this programme. So the focus on measurable and bodily-based outcomes is not the exclusivity of the health services. The diagnosed body is defined and assessed through its organisation, by institutional territorialisation. The ACTIVE programme, which vowed to empower people, may have been disempowering to those excluded on the basis of bodily assessments only.

This paradox may be linked to time, as it is defined either institutionally or personally. As in the case of the ACTIVE programme, in institutions assessments tend to be based on *present* bodily (mal)functions. People, on the other hand, live with the condition day-by-day and the time spent with the disease fashions their perception of need. So there are two notions and definitions of time at play in the service. The institutional one is physically based and relates directly to bodily function, to the visible degree of impairment engendered by the disease. The experiential one is longitudinal and encompasses people's life as a whole. While this experiential time may be appreciated by professionals, this does not influence the selection process.

#### **b. Illness trajectories: time since living with MS**

Participants described their experience of being diagnosed with MS and the changes that occurred in their life as a result of it.

When you are given a diagnosis of something like MS your whole thoughts about how you should live changes. The goal posts change. Things that might have seemed so big and important aren't any more. You know, it's what you are getting out of life itself that matters. Whereas at one time you might think I want to work because I want to buy that and I want to give the kids this, that becomes irrelevant because you just hang on to each day - you make the most of it. So I think it is a life-changing thing in many ways and quite often for the better (Jane).

Paterson et al. (1999) describe life with long-term conditions as a 'transformational experience'. This is an evolving process, which happens through the individual learning "to restructure the self and the illness experience through the differentiation of the self" (1999: 799). This process happens over the experiential time of the person living with the condition and is illustrated in the following quote from one of the participants:

I had been told I had MS. And I felt this is the end... this is the end!  
But really as the years have gone on, it was just the beginning. I have  
been diagnosed nine years in November and I am still on my feet...  
(Terry)

Both Jane and Terry seem to have been able to live MS as a positive thing by abandoning the focus on now unachievable goal posts. In doing so, they embrace the uncertainty of the disease as being the uncertainty of life itself, with which every human being has to live. They have developed a BwO that enables them to deterritorialise themselves from previously occupied roles. Embracing uncertainty has been conceptualised as located within a transformational (deterritorialising) framework that includes, but is not limited to, notions of stress and coping (Parry 2003). This happens in a dialectical relationship between the uncertainties of future bodily happenings and the certainty of knowing who one is and what one values. The BwO operates this dialogue between one's unconscious and one's bodily possibilities. This is a deterritorialisation in time, which allows the person to favour the present moment rather than project herself in some unpredictable future.

Other participants talked about the difficulty of accepting a diagnosis of MS. They implied that as long as people could not accept their diagnosis, they lived their lives in a constant negative comparison to their past healthy selves.

I have met a lot of people with MS who haven't really accepted it.  
They are living their lives in denial. They know that they have got  
MS, but they are not willing to talk about it or mix with people in  
wheelchairs or sticks (Terry).

The following participant seems to fit into this description of disengagement with MS. He had a wall of his living room covered in trophies of past physical achievements and certificates of participation in a wide variety of sporting events, at a competition level. During the time – space of the interview, he described his experience of MS in a constant referral to a past life that he no longer had. "I can

remember two years ago. I could walk without a stick, but I can't walk without a stick now. So that is how it has progressed you know" (Mark). Others referred to their past in explaining the current frustration of not being able to achieve results at the same pace as previously experienced. "I'm about quarter the speed I was before, which frustrates me rather a lot" (Frank). For these people, the past is a constant yardstick against which to measure current bodily (mis)happenings. They are territorialised by their body and its past healthy possibilities.

The time of experience, which is lived, does not in its longitudinality always match the time frame of institutions that is punctual, measured and predominantly physical. The following participant describes herself on the verge of becoming recognised as 'disabled' in society, but not quite there yet. Because physically she appears well enough to work full time, she cannot be granted the financial support that would enable her to reduce her hours and lead a fuller life.

I'm having to work full time, my job is my life ... and I'm absolutely exhausted ... At the end of the day I come home, sort of do what needs doing ... I'm ready for a bath and bed. And that's my life. I have no social life at all (Denise).

Fatigue is experienced and has unseen consequences, which cannot always be measured. Although it is a medically recognised and commonly experienced symptom in MS, it is not granted credibility in the wider society, because it cannot be seen or measured. This leaves people with little physical impairments in a limbo state, where they feel they cannot live the way they used to, but can neither move on into any other kind of life. They are territorialised by the functionalist paradigm that underpins institutional guidelines, and this leaves them with no energy to think of life differently.

### *Uncertainty*

Many participants reflected the society in which they lived in seeking facts and certainty in their lives. MS introduced an element of obvious or certain uncertainty that people did not always welcome. "I would just like to know in the future in what condition I am going to be... which obviously nobody knows" (Terry). Another participant highlighted the relativity of living with uncertainty and the often-irresistible temptation to seek certainty:

I do believe if you can't handle the answer don't ask the question, you are always tempted 'Oh what is going to happen to me in 5 years time?', I could be knocked down by a bus tomorrow... One or two members of the group had to be wary of [that] sometimes (Frank).

People wanted to be able to prepare themselves for predictable bodily happenings and all that was offered to them by professionals was the uncertain nature of MS. People who had moved on from this need to prepare and plan ahead, had embraced the unpredictability of life as a whole. In their case, the information sessions could at times have a negative effect, because of the attempts made to tell people what may happen to their bodies:

At times maybe the information was given to you which may or may not happen to you and I know some people want to prepare for that, in my case you know I will sort of want to continue with normal - inverted commas 'normal life', as long as possible and I do believe in mind over matter in many instances and if somebody tells you that is going to happen, sometime you let it happen (Frank).

So not only have these people managed to see life in a different light, one that does not require bodily predictions, but they could also see case scenarios or predictions put to them as having a detrimental effect. Frank may be seen as being in denial, but he may have operated a deterritorialisation from his patient position, with its invisible bodily happening that may or may not lead to visible impairments. He takes his focus away from the condition and its possible trajectories to focus on his life in the broader sense. Certainty is a territorialisation. Professionals, in attempting to predict people's bodily happenings, reinforce this territorialisation.

The following participant explained how she had been through this process of changing her outlook on life and how she thought other people needed help through it. She recalled one of the speakers during the programme:

I mean we did have a girl with MS and she was really really brilliant ... she was really good at talking about our future towards the MS, how to try and think, but I think really you do need sessions with a counsellor if you are needing to change your way of thinking (Jane).

According to Jane, what people with MS need to be able to deal with an uncertain future, is to change their way of thinking, or to work towards a deterritorialisation from their past selves. This involves challenging deeply ingrained beliefs and assumptions about future plans and the control one has over one's life. The



programme gave Jane the confidence to face her future in a more open way with her family:

At one point I thought well if I have grandchildren I am going to be frightened of looking after them and I talked this over with my husband and certainly I feel more confident now that it isn't going to be a problem. I think that is something else that the programme has given me, better confidence to look at things like that (Jane).

In this instance, her way of dealing with uncertainty was to accept it to a point that she was able to verbalise and share it with her life-long partner. Uncertainty is lived and embraced, not only in a bodily sense, but also in one's social environment.

**c. Coming to a shared space and time: the group sessions**

"You tend to become like isolated you know..." (Michelle). This participant expressed the importance of finding new, shared spaces in a life with MS. Because she was no longer able to join in with previously shared activities in her immediate social environment, she had lost contact with a lot of people. Other participants described how their MS had isolated them too and they had found it difficult to build new social networks. People are not only territorialised by their bodily possibilities, but also by the social environment in which that body evolves and interacts. Professional support was described as scant in helping people to deal with this, as was the case with other MS matters: "You're told and that's ... there's no cures... you go and you wait" (Lesley). This illustrates the limits of the organ-ised body in that within this paradigm there is no hope and little support, no alternative is offered beyond the explanation of the body's micro-happenings.

Echoing these comments, many people described how they enjoyed the group sessions:

It is nice meeting other people, you know that are in the same boat as you. I mean one other lad that was on it, I know where he lives and I got to know his wife so I'm going to call and see them (Gill).

Some relationships shaped during the sessions outlived the programme. People contrasted the programme with other MS support groups:

Well I enjoyed that [the group sessions] ... fair enough it was in the hospital gym but you were in a group and it was run like a keep fit

session that you would have in a community hall and that was nice and also you are making new friends so it opens up your outlook (Jane).

The difference to MS support groups was in the physical focus of the exercise sessions. Because people had to move around to follow the circuit of exercise designed by Lisa, there was a predominant feeling of shared space in which people had to move and which encouraged communication. Another distinction was the focus brought to the ACTIVE sessions:

Sometimes they might have a speaker on who is really interesting and you learn something... I've been to [groups] where you go in and everybody will sit around the table and just complain and moan, well not moan, but just talk about events without any constructive outcomes if you like. It's just sitting and complaining. I think, 'I could do this at home!' I need something more than that. I need something to happen (Carol).

What Carol describes is the way in which people who are brought together because they share a diagnosis are maintained within the paradigm of the organ-ised body. Because they are at the core of this territory, they cannot see beyond it and the only comfort they can find is the knowledge that they share their fate with other bodies. Many participants to the ACTIVE programme disagreed with this view and valued either the information sessions or the exercises on offer to them. This is further illustrated in the following quote:

The group sessions were fine I think the dynamics were good, the camaraderie was good and everybody... well we had a good sense of humour and because you have all gone through similar problems you know and there was an openness and I think the group was supportive ... I enjoyed going, I enjoyed meeting the people there and I like to think I contributed to the group in some way (Frank).

The shared space facilitated communication, so that experiences could be shared too. The movements of the bodies created an atmosphere of informality, where people felt able to talk openly about their time with MS. For the physical activities, the group ensured motivation was maintained and emulated throughout the course. "When you do it on your own you do tend to think, 'Oh I can't be bothered' but if everybody is doing it, you have a specific time when you go" (Carol). The exercises encouraged people to apprehend their bodily possibilities and the space around them in a different way.

#### **d. Empowerment and quality of life**

A lot of people explained how the diagnosis of MS and the subsequent lack of support from the health services had left them feeling disempowered. The course had enabled them to regain some confidence in their ability to use their body.

[MS] takes your confidence away.... doing that course sort of gives you more confidence and you realise that there are things you can do, you're not totally useless (Gill).

Many participants echoed this positive feeling of being enabled to 'do something'.

And I am putting my heart and my soul into making me feel better in the way I am actually doing something about it. I know there's no cure. I know that and I understand. But I am doing something about it (Terry).

In being diagnosed, these people's body has been MS-ised. The professionals' advice to avoid physical exercise has taken away their opportunities to move their body in different ways. It has maintained them in an organ-ised, MS-ised territory. For some people, the body had become something they had to live with, over which they had no control and which they were frightened to use, in case they would make things worse. Their body was a cross they had to bear in a territorialisation that prevented them from moving forward and seeing beyond it.

One particular participant, Jane, was so enthusiastic about the course that she agreed to share her experiences with the participants of the following round. The handouts for her presentation are presented in figure 2. Echoing other participants' comments, she describes herself as a previously disempowered body, at a loss in the lack of professional support she had received since her MS diagnosis. For her, the programme had a noticeable physical impact, as her balance and gait were much steadier at our second encounter. This had an impact on many other aspects of her life, as she explains in figure 2.

Figure 2: Jane's handouts for her presentation to the second round

The Active Programme – a strange title for a programme aimed at patients with MS isn't it? I mean aren't we supposed to 'take it easy, rest, don't overdo it'. At least that was the impression I was given when I was diagnosed.

I didn't know anything about MS then. I thought it couldn't be good news going on the neurologist's expression but I didn't really know what the diagnosis meant and I was too scared to ask. Anyway it

didn't matter. People around me knew what to do. So I 'took it easy', didn't overdo things and took the tablets and rested, and rested until something inside started to scream. My life hadn't only changed but it wasn't my own anymore. It belonged to this MS thing that I knew nothing about and which I had no control over. This was a disabling experience, in the sense that I had no choice and no control over what was happening to me. I wasn't sure who to talk to either.

Although the programme is drug free there are side effects. For me, as my fitness levels developed I felt stronger, particularly in my legs. My balance has improved and I feel that there are times when I don't need to use my walking stick. But best of all I feel well, less fatigued and I am more able to lead a much fuller life. It has given me a strong sense of feeling good and more content as I get more out of each day. My self-esteem has risen as now I can do more for my family and myself.

I probably would never have gone to a sports centre on my own because I felt uncomfortable with the idea that people might not understand my individual needs, and that I would feel intimidated by it. However, having everything organised and having already met the fitness advisors as well as going with someone else with MS, gave me the courage to give it a try.

Now my friend [fellow participant] and I have moved onto the exercise on prescription programme and go regularly to the gym and in the pool. We still pace ourselves and take frequent rests but in doing so we can still achieve. Each week I can feel my fitness increasing and my quality of life improving. Although I still use the work/rest routine to manage fatigue, everyday tasks seem so much easier. Housework is no longer the chore it used to be.

Jane's five most important life areas are represented in table 7, before and after her participation in the programme.

Table 7: Jane's most important life areas, presented by order of importance and (satisfaction level)

Pre programme SEIQoL areas	Post programme SEIQoL areas
Family (100)	Health (80)
Friends (20)	Family (80)
Garden (50)	Mobility (90)
Time on my own (40)	Socialising (100)
Reading (60)	Gardening (80)

The five life areas are presented by order of importance to her (cue weight), and the level of satisfaction with each of the areas are represented in brackets. Her overall

quality of life score did not change markedly between the two measurements, from 81.3 (before) to 83.5 (after). However, the choice of areas and their associated levels of satisfaction are worth considering. It is quite common in using SEIQoL that people will easily select two or three areas of importance in their life, but many have to think a little longer to find a fourth and fifth area. For Jane, family, friends (or socialising, assuming it would be acceptable for her to assimilate these two areas) and gardening came quite spontaneously. It is quite interesting that her satisfaction with these three areas increased after the course, but also that they had become less important to her by the end of the programme. What really made the change is the selection of the two remaining life domains: 'reading' and 'time on my own' before the programme, and 'health' and 'mobility' after. By the end of the programme, these were amongst the most important areas, with very high levels of satisfaction. During her interview, she explained this change and highlighted how the course had enabled her to look at the future in a more positive light and to embrace its uncertainty more fully:

I think keeping mobile is quite important to me now. I used to, before the programme I was thinking I know where I am at now and I know what the future might be nobody can tell me what it is going to be but I know what it might be and in that case you know if I can't do anything but read a book that's fine. Whereas now I feel you know I can get out there and do it (Jane).

It took the ACTIVE programme to make her feel able to take control of her own health. Questioned further on the reasons for this change, she explained that it had become important to her because she felt empowered to do something about her health. After her diagnosis, because there was no known cure for MS, professionals had advised her to be the passive observer of her bodily happenings. As she describes it, this was a 'disabling' experience. After the programme, she was still conscious of the fact that there was no cure, but now felt that she could regain some control over her body. This had pushed 'health' and 'mobility' to the centre of her new concerns.

Before the programme health wasn't an issue as such; I thought well I am like this because I have MS... Now I can see how I have been through the programme and can feel an improvement in all areas of my life I kind of feel well health is important... Now I can see a way of maybe improving my life regardless of the MS... I am looking at things differently which is you know, keeping mobile is more important than reading a book... and I think emotionally I am definitely better (Jane).

The programme has helped Jane to deterritorialise herself from her MS-ised, organised and dysfunctional body. This does not mean negating their existence, but rather to apprehend them differently, through their possibilities rather than through their impairments or the restrictive power of uncertainty.

A few participants disputed the sometimes-assumed centrality of MS in their lives. "The issues that determine whether I am happy or not tend to be not necessarily related to my MS, it tends to relate it to the rest of the family" (Frank). A diagnosis of MS made other participants aware of their life and health and drove them to be very proactive in looking after their body.

[MS] probably made [my quality of life] better. That might sound silly. We took the decision to join the gym purely as a way of me keeping my health really, keeping my fitness. Since then I've made a very conscious decision that I would reduce my own stress levels because I think personally that's one of the triggers, that's been one of the triggers for me and I also take a bulk load of multi-vitamins I feel the healthiest I've been ever. So really in a lot of respects it's improved the quality of my life (Michelle).

For Michelle and others like her, the added benefit of the course was in the information sessions. Possibly because she had taken control of her body since diagnosis, health was central to Michelle's quality of life. Right from the time of diagnosis, she has sought to actively territorialise her body in terms of its possibilities rather than impairments.

Although Jane was the only one who so clearly and strongly expressed herself about the course, these feelings of a recovered sense of control over one's own body and condition were evident through many interviews:

[There should be more programmes like the ACTIVE programme] because then you don't feel like you're out on a limb... You know, you feel like you're just, you're told and that's it... And, 'Go home! We can't do anything for you' (Lesley).

If you just sit back and don't do anything, then like physically you're just giving in to it. If you go out and do something I mean it might not be actually physically doing something but learning about it, at least you know that you're doing something to help yourself (Carol).

For some, empowerment could be about making health care decisions for oneself, which on occasions could go against professionals' advice:

I was on tablets from the doctors but I knocked them on the head because I didn't like being on long-term medication. So I stopped them ... I felt as though I was becoming a zombie (Frank).

Other people's comments echoed this: "I don't think [my consultant] is used to having somebody who will question what treatment is... I do question the treatment given to me" (Denise). Empowerment was also about taking what one felt one needed from the ACTIVE programme:

I did the initial six weeks course, which was the information sharing. The second part was the physio erm, in the gym and stuff like that and the third part was the swimming, neither of them I did because I go to the gym regularly, about three times a week and I go swimming as well. I didn't feel that I needed that. But you know the initial six weeks, I found that very beneficial (Michelle).

The steering committee of the ACTIVE programme was very concerned about the dropout rate and spent a considerable amount of time trying to accommodate people who, like Michelle, did not attend the exercise sessions. This was negating people the initiative to take from the course what they felt they individually needed, and therefore in some respect going against its own empowering philosophy.

A recurrent theme was that before the programme people would not have known what type of exercises to do and how much to exercise.

Unless somebody shows you like that, you don't know whether you are doing the right things, the wrong things or how far to push yourself. So yeah it was very, very useful, yeah (Gill).

In many cases, the course had taught people to listen to their own body and work within their individual limitations.

When I was going to the gym I was just doing the exercises that I knew I could do, I was never trying to ... Push myself, I was doing what my body could take and I felt fine (Robert).

The course enabled these people to re-acquaint themselves with their body and its signs. Prior to it, many felt professionals had taken over their body, as "they knew best" (Jane) what should be done. In the MS-isation of their body, people were taken into a territory previously unknown, in which they did not have either knowledge or power. The ACTIVE programme enabled people to re-learn their bodily limitations in a controlled and professionally driven way, so that they could move beyond them. Prior to the programme, participants were concerned that they might damage their

body further – a damage that could only be assessed professionally or measured through technical means.

The physio made me realise how much mobility I had lost and how much I had to keep it up if I didn't want to lose it all... It's working because... the pain is better than it was 6 weeks ago when I first started (Denise).

Other participants, who also described how they felt encouraged to adopt a proactive approach to their physicality, echoed this:

The fact that I have physio has taught me how to help alleviate the pain... I feel I should be doing something, not just sitting back and accepting it... Fighting it if you like (Carol).

#### **e. The ACTIVE programme and quality of life**

When asked about the effect of the programme on quality of life, most participants highlighted its effects beyond a possible bodily reality of improved mobility.

[the programme] gives yourself confidence and ... which is like a major thing really I think but if you feel better in yourself you feel physically better... like I say I think it goes in a circle doesn't it, you know if you feel better about yourself you physically feel better and vice versa (Gill).

Gill also explained why her important life areas had changed since the beginning of the project:

You see probably before I mentioned those things (washing, ironing, cooking, food shopping) because I couldn't do them and that's what I was finding so hard whereas now I can do them without thinking, that's how much better I am... It was amazing the difference that it could make from me going in to coming out of the sessions, how much better I felt (Gill).

Others were not quite as explicit, but nevertheless expressed how happier they felt: "Don't ask me why, I just feel happier now than I did than I went on this programme... I feel fitter as well" (Robert). Robert went on to explain how he had changed his whole attitude to life, how he was much calmer, relaxed and generally 'enjoying life'. He was attributing this to the programme. This positive attitude towards life in general seems to have been shared by other people.

I learnt not to be negative... I suppose it makes you think about your quality of life more. I suppose it makes you respect what quality of life you've got. I don't think I've got a bad quality of life really. I feel definitely more positive (Russell).



The programme facilitated a deterritorialisation that enabled people to stop thinking about themselves in MS-ised ways and view their life and body in terms of their possibilities. They still sat within an organ-ised paradigm, but had shifted their emphasis within it.

Other participants had been feeling in control of their life and body before the start of the programme. For them, although they enjoyed the course and often noted a physical difference in their body, there was no such drastic change in quality of life:

It [the programme] didn't have an impact in that respect on my quality of life because I won't let the MS interfere with my quality of life, so it didn't improve, it didn't sort of, didn't talk me sort of into doing anything I wasn't doing, and it didn't encourage me to do any more than I'm already doing because as far as I'm concerned I won't let it get on top of me (Frank).

Frank had rejected the MS-isation of his life and had already operated the deterritorialisation that enabled him to see his life differently. The benefit of the programme was for him on a simple functional level. In contrast, the programme as a whole was a trigger for Denise to take stock and proceed to a full life examination:

Before ... it [MS] was at the back of my mind, it took the course to make me face up to what could happen and I have. It's had me thinking and feeling quite depressed... but I do feel that I'm coming out of that now, so it's a positive thing making me face up to things. The negative side of it is my reaction to it but again, I had to do it... The course did make me think about my priorities and if there are any problem areas in my life, it made me face up to things (Denise).

The course did not only enable Denise to regain control over her body, but also over her life in a broader sense. Her life was not territorialised by MS in the sense that she could live her previous life in spite of it. However, the course has enabled her to apprehend her life differently, in a way that appreciates MS but is not dominated by it.

#### **f. When disowned bodies got ACTIVE**

Although some people were assiduous in their attendance to the ACTIVE programme, others were inconsistent in their presence, particularly to the exercise sessions. For some, this was because they saw these as redundant with the exercise regime they were following of their own accord. Others had different priorities in

life at that time: one person, for example, had been moving house, another participant could not find childcare during school holidays, another simply felt well at that time and 'could not be bothered'. These people avoided or objected to forms of bodily surveillance, implicitly or explicitly questioning the utility of the programme for them, in their own time – space. Yet for the regular attendees, who all benefited greatly from the programme, the sessions provided a social space in which relationships were cultivated. The time and shared space of the group sessions empowered people by providing them with the means to be active about their condition. Although the conditions of this activity were regulated and monitored, this was seen as better than the passivity previously fostered. Beyond the programme, the group sessions, where physical movement was encouraged, provided a space to meet, share and as Frank (1996) shows, cast stories.

Some of the participants had been exercising against medical advice and had maintained a level of ownership of their own body. The programme enabled the other disowned bodies to re-acquaint themselves with the person they were. Participants learnt what they could do, how far to 'push themselves' and welcomed the opportunity to 'do something'. At the same time, by being selected for their level of physical functioning to be part of the programme, their bodies had been normalised. Foucault (1977) considered normalising judgements as practices that divide and classify people, distinguishing those who are normal from those who are abnormal. In health and medical domains, normalising judgements can be identified in diagnostic tests or assessment procedures that classify people by severity of disease. The aim of the programme was to empower people to take control of their own disease trajectory. Yet the criteria for inclusion in the programme were established through technical means of, for example, the Kurtze Expanded Disability Status Scale (EDSS- Kurtzke 1983). This may have alienated from the programme people who would have benefited from it. Although most participants felt empowered, they had been selected and only had the power not to attend some of the sessions. Other bodies who would have applied to be part of the course were rejected and did not have the power to question this decision.

However, participants were not the passive recipients of professional control, but were instead active in the creation and negotiation of the social world of the

programme. For example, one participant chose, unbeknown to Lisa, to write to his consultant with his support for the programme. Historically, the programme had received little support from local consultants in neurological conditions and this letter proved to be greatly appreciated by Lisa who had put much of her personal time and energy into its set up. So power was exercised and power was shared during the programme, in a way that enabled some people to feel more in control of their body and their life in general. The power exercised in the sessions elicited, for some participants at least, a sense of empowerment and productive possibilities. Bodily, self and social transformations were made possible by the disciplinary techniques and the shared time - space of the ACTIVE programme. Unusually, the programme brought together the organisational power of professional knowledge with an opening up of the possibilities of deterritorialisation for many participants. This, however, remained within the framework of the organ-ised body and therefore the deterritorialisations operated were relative rather than absolute. They were framed by professional knowledge and what the ACTIVE programme highlights is the existence of liberating and empowering possibility within an organ-ised framework. Bodies are re-territorialised in a muscles and nerves territory over which they had lost control. The ACTIVE programme enables them to explore and gain control over the territory of their MS-ised body. This both extends and reinforces the boundaries of the MS territory and offers a time limited remedy to the MS-isation.

## Empowerment and Disempowerment

Empowerment to live with one's bodily ailments is seen as the answer to a life whose uncertain future is brought to the fore by the illness. In postmodern, Western and individualist societies, agency is a core concern and the empowerment of patients and front line staff feature highly on the agenda of the NHS (DoH 2001a). Empowerment is defined as: "1) The giving or delegation of power or authority; authorisation. 2) The giving of an ability; enablement or permission" (Collins English Dictionary 2003; emphasis added). The gift of power presupposes an initial imbalance, which locates its source in professionalism. The policy trend on patient empowerment therefore disregards the possibility of power as being shared, mobile or negotiated in social and medical encounters.

The initial power imbalance is maintained through an actualisation of 'empowerment' that denies prior agency. Foucault introduced the term of 'subjectification'. This, as Frank describes it, is a "slippery term" (1998: 332), which can have positive connotations of personal ethical achievement - to become a subject - as well as echoing Foucault's earlier concerns about repressive power - to be subjected to something (Frank 1998). According to this, empowerment can be conceptualised both as a subjectification of the self, which depending on circumstances can connote self-agency and mastery of the self in long-term condition, and exactly the opposite: disempowerment. The relationship between these two conceptualisations is less of an 'either / or' than it is one of 'both / and'. People experience subjectification in both its connotations through their bodily (im)possibilities and the social, environmental and medical background of its happening. Empowerment and disempowerment are therefore not dialectically and hierarchically situated, as is often assumed, but rather reflect the possibilities of subjectification. Petersen and Lupton (1996) assert that:

Attempts to 'emancipate' or 'empower' marginalised groups ... may be regarded as ever more complex ways of defining, regulating and normalising the members of such groups (1996: 180).

Through the concept of subjectification, techniques and processes of empowerment may reproduce socially and medically structured knowledges. Rose (2001) describes blurred boundaries between coercion and consent, when people are exposed to new discursive practices, which translate aspects of their self into thought and language. The quality of life

discourse in long-term illness is one example of this, as it gives rise to the possibilities of subjectification, in both its possible meanings.

Frank asserts:

Calls to 'liberate' aspects of oneself can all too easily become techniques - often copyrighted and marketed - by which selves control themselves in the cause of the promised liberation (1998: 338).

Health promotion and the enforcement of treatment regimen can be such calls to liberate. The call is for the person to become a body that is docile to the demands of the 'liberating' healthist or rehabilitative practices. Frank (1998) highlights how any practice of freedom can easily become commodified, institutionalised and routinised into techniques of the self, which enable the operationalisation of power. Liberation - rehabilitation, health promotion - discourses can become techniques of power, normalising the subject even more effectively than diagnostic categorisation, because the subject becomes the acting principle of his or her own normalisation (Frank 1998). In the television programme *You Are What You Eat*, people are subjectified to eat healthily and lose weight. In the ACTIVE programme, participants are subjectified in that they become the agents of their rehabilitative possibilities.

Koch et al. (2004) studied self-management in long-term illness. For their study participants, self-management was about reclaiming the self and regaining full human identity. They highlight that much of the literature on the concept focuses on compliance with treatment regimens and dismisses self-agency. In their study, people had developed a sense of mastery over their condition, and self-management related to the activity they were undertaking to create order, discipline and control in their lives (Koch et al. 2004). People had become experts in management of the self through a long learning history. They were able to conceptualise and use life events, as well as to manipulate their immediate environment, in order to suit their current situation and enhance their health. When medical help was sought, it was the patient's decision to enter this model of care, rather than a health professional benevolently deciding that this was the best course to take. These people were in charge of their self, their condition and its management.

The politics of beauty and health described in previous paragraphs mean that we often consider the 'abnormal' or impaired body at best as the belonging of an unfortunate soul and at worst, that of a deserving sinner. Whilst the person with a long-term condition may be more

finely tuned to their body than most 'healthy' people, society at large is disinclined to acknowledge the link between an impaired body and its person (Barilan 2005). Talks about disease management are based on such an assumption about the separateness between the condition and people's lives. Koch et al. (2004) dispute this, in showing that people who had been considered as 'expert patients' were also experts of the self. Their bodies are without organs, as it is not the *organic* nature of it that dictated their actions. Organs are classifications made by experts of the body, through their bio-mechanical knowledge. From the moment that a body is with organs, it is therefore dis-empowered in an absolute sense, as intensities of life are negated and made organic.

The provision of information is seen as key to the empowerment of patients, and has become a central tenant of the UK government's health policy (DoH 1998). However, fundamental problems with this informed patient discourse have been highlighted. For example, Dixon-Woods (2001) argues that the dominant discourse in patient information leaflets privileges biomedical over other forms of information and adopts a one-way model of communication. Ideally, patients would take it upon themselves to seek information about their health conditions and possible treatments, while their doctors would listen and negotiate treatments, taking their interests and values into account (Henwood et al. 2003). Henwood et al. argue that "there are very real constraints on the emergence of the informed patient identity" (2003: 604). In their study of menopausal women's attitudes and decision-making processes regarding HRT, these authors found that many of their participants did not want to seek information by themselves, and were quite happy to trust their general practitioners' advice. This is important in the context of the 'rights' agenda in the current discourse of informed patient, or reflexive consumer. The 'rights' advocated in policy literature carry 'responsibilities' that some patients, according to Henwood et al.'s (2003) study at least, are not willing to accept. Moreover, in theirs, like in other studies, practitioners showed reluctance to engage with lay-led decision processes when these were at odds with their medical knowledge. Henwood et al. conclude that "the informed patient will not emerge naturally or easily within existing structures and relationships" (2003: 605). This is because these are based on an organ-ised paradigm that assumes an imbalance of knowledge between the expert and the person with a diagnosed condition.

Fox et al. (2005) studied empowerment, in relation with the concept of the expert patient, in overweight people using an internet forum. In their study, when patients were empowered,

the benchmarks remained set by biomedical norms of acceptable behaviour (Fox et al. 2005). They forecast three possible futures of the expert patient movement. Two of those see the spatial extension of medical power, either through an extended professional gaze into expert patients' lives, or through the lack of questioning of medical dominance. The third possibility, more positive, makes extensive use of international consumerist movements, in that consumers of health care receive information and become empowered out-with the medical discourse (Fox et al. 2005).

This carries vast consequences for policy documents, such as the NSF for Long-Term Conditions (DoH 2005), which see information as the key to empowerment. In these, information is provided from recognised sources only, and empowerment may be limited to choice between a set of treatment options. In contrast with this focus on the notion of informed choice, Shakespeare (1998) stresses the importance to explore the broader social and cultural context in which decisions are made and the "relative availability of clinical versus experiential knowledge" (1998: 665). Choice does not exist in a vacuum, but is structured and influenced by the individual's wider social environment.

The concept of responsibility, however, presents a paradox (Byrne and McQuillan 1999). It would be common sense to say that a responsible decision can be made on the basis of knowledge: only if we know all there is to know about a condition can we act responsibly towards it. However, suggesting that a decision can only be reached under certain circumstances and with a determinate amount of knowledge, would be limiting the possibilities of the concept. As such then, this would not be a decision, but a programmed deployment of knowledge, which presupposes that when we know enough, we can stop thinking and make an 'informed choice'. Current empowerment discourses require us, as patients, to do just that and so to act irresponsibly with regards to the formulation of our responsibility, which as a moment of decision must remain undecidable (Byrne and McQuillan 1999). So not only is power a more fluid entity than the concept of empowerment may lead to assume, and carries its own possibilities, but political power carries its own contradictions in requiring us to negate our sense of responsibility by fixing it in time and space.

## **The National Service Framework for long-term conditions**

The overall emphasis of the document is on “supporting people to live with long-term neurological conditions, improving their quality of life and providing services to support independent living” (p5). In the context of long-term care, ‘cure’ is no longer a treatment goal. Rather, the intended outcomes focus on reducing the impact of disease on, for example, quality of life. This is done by subjecting the body to an array of surveillance measures, in the form of the recommended care plan from diagnosis to death. Independence and quality of life are seen as core concerns for people with long-term conditions throughout the document. Other concepts underpinning it are the distinctions between health and disease; time and space; and patient centredness and empowerment. This chapter will explore these themes as they are exposed throughout the NSF, and deconstruct them one by one.

### **a. From diagnosis to death**

A key feature of the document is the development of an integrated and comprehensive care plan, designed to address people’s complex and changing needs in a holistic manner. It is seen to be “key to improving [people’s] quality of life” (p20). In particular, the care plan should be:

considering services and support to enable people to play a full, inclusive role in society, including housing, transport, benefits, education, careers advice, employment and leisure (p20).

The assumptions underpinning the establishment of the care plan are therefore that people with long-term conditions necessarily have a poor quality of life and that organised management can improve it. Health services are to co-ordinate other services in order to enhance quality of life. This integration of efforts assumes a multidimensional attribute of the diagnosed subject, which may contrast with historical medical approaches that focused on the organ-ised body only. In that sense, the NSF represents an extension of the service’s focus to include the physical and practical consequences of the bodily disorder. However, it may run the risk of keeping the diagnosed condition as a central focus in people’s life.



The first Quality Requirement (QR) is termed as follows:

People with long-term neurological conditions are offered integrated assessment and planning of their health and social care needs. They are to have the information they need to make informed decisions about their care and treatment and, where appropriate, to support them to manage their condition themselves (p19).

Integrated assessment and planning procedures organise people's lives in clear, predetermined and predictable patterns of care reminiscent of the codification described by Foucault (1973). Services are refocused from the organ-ised, discursively produced body, to the body that is organised in time and space. The health services provide information to people, so that they can make informed decisions. However, the source and type of information is pre-determined and, as such, necessarily limited. As a result, the choices on offer are limited within the parameters of acceptable practice too. Shared health and social care case notes and decision-making processes are deemed to

limit the development of predictable secondary complications to the disease, increase the effectiveness of other interventions such as rehabilitation and promote the quality of life for people, their families and carers (p19).

This assumes a linearity and predictability in the disease trajectory, where current action can increase control over future bodily happenings.

Reith (2004) studies the notion of risk in society and shows how medieval narratives of temporality explained uncertainty through a superior power, in which the future was pre-determined and out of reach to human intervention. She describes how this system was then eroded in favour of a gradual "colonisation of the future" (2004: 384), brought about by the advent of a system of global capitalism. She asserts:

such socio-economic upheaval engendered new notions of temporality and human agency, expressed in the optimistic Enlightenment belief in the possibility of eliminating the uncertainties of the future through rational action in the present (Reith 2004: 384).

This perception of the future as something amenable to intervention cleared a space for the emergence of the concept of risk as a "means of calculating - and so controlling - the uncertainties of that future" (Reith 2004: 384). Much of the NSF is based on such an assumption of risk as real, rather than as a probability based on calculations using population data, which may have little bearing for a particular

individual. One of its key features, the care plan, is designed to regulate the present in order to diminish future risks of secondary complications.

In the NSF, it is recognised that people may present simultaneously with a broad range of needs, which are to be addressed holistically by a range of professionals. The organ-ised body has assumed temporal and spatial dimensions and repercussions. These are to be classified and ordered as much as possible in predictable and preventable categories. The spaces occupied by the organ-ised body have to be organised so that needs may be addressed. This extension of the organisation from within the body to the spaces it occupies runs the risk of keeping the diagnosed body and its treatments as central to people's lives at all times. For example,

those providing rehabilitation and support services can train those providing day to day support, to make sure that rehabilitation becomes part of everyday life (p48).

The integrated assessment and care planning are also seen to improve the "opportunities for social participation" (p19). The territorialisation of the body by the medical discourse is extended physically to surrounding social spaces, but not conceptually, in that the body with organs is kept as a core focus. For example, community rehabilitation in QR5 is both multidisciplinary and centred on the person's home. It is seen to have the potential to "help people reintegrate into the community" (p35). So the medical discourse extends into the social spaces of diagnosed bodies and is based on the assumptions that people become alienated from their community when they are diagnosed with a long-term condition. A key aspect of service intervention is to help people maintain their independence within their social spaces.

## **b. Independence**

While 'independence' or 'independent living' are mentioned 38 times over the introduction and the first two chapters, these terms are not clearly defined at any point in the document. In the first chapter, *Setting the Scene*, neurological conditions are described as causing:

A range of different problems for the individual, including: Physical or motor problems; Sensory problems; Cognitive / behavioural problems; Communication problems; Psychosocial and emotional problems (p10-11).

It is this problematisation of life with a long-term condition that defines independence for the document. From this viewpoint, someone independent has a fully functional body, a mind that functions 'normally' and is able to communicate through ordinary and clearly understandable language. The NSF frames people with long-term conditions as inevitably and progressively dependent, without questioning the concept. For example, one of the aims of the NSF is to "provide personal care, support, equipment and accommodation planned around [people's] needs" to enable them "to retain their independence" (p16). So the independence that is valued in the NSF is a physical independence, attached to the ability to perform the mundane tasks that all of us have to perform daily. Yet a person with long-term conditions may have a limited amount of energy that they may want to save for less mundane tasks (Paterson et al. 2002).

Another version of independence emphasised throughout the document is that of living independently. In QR7, the provision of appropriate equipment and adaptations is seen to "support people to live independently" (p43). This is based on the following rationale:

People with long-term conditions can find it difficult to maintain their independence in the face of increasing disability. Providing up-to-date and appropriate assistive technology / equipment and home adaptations can help people to live with their condition and promote social inclusion and independence (p43).

If technology can help to live with impairments, then life without it is framed negatively, because of the possibility of the need for assistance. Equipments give more independence, which helps the person live in spite of her body. The body is organ-ised in such a way that when an organ loses its functioning potential, it has to be technologically supported or supplanted. Technology is supplied in order "to maintain people's abilities and prevent deterioration" (p44). The NSF problematises the malfunctioning body and places it in a medical curative model by addressing impairment through the provision of aids and adaptations. Even though these technologies alter the physical space in which the person evolves, the locus of the problem to be addressed remains the individual and her impairments. To live

independently, like to be independent, is socially and medically determined not to include a level of dependence to perform tasks of daily living. The organisation of the body is extended so that maximum control is retained over the physical spaces occupied by it.

QR8 aims “to enable people with long-term neurological conditions to achieve maximum choice about living independently at home” (p47). Life at home is valued, but is also presented as the favoured possibility. A footnote clarifies that “‘home’ in this context means the place where the individual chooses to live, which may be their own accommodation or may be a residential or care home” (p47). However, the financial drive of the health services to maintain people in their own home as long as possible is very clear in the document. It is less costly to provide someone with expensive technology so that they can perform a task on their own in their home, rather than pay people to assist them with it (QR7). Equally, it is cheaper to maintain people at home on the long-term, rather than having to provide places in institutional settings (QR7 and 8). So independence is bodily driven, but also financially advantageous for the health services. Indeed, “supported living options”, while offering “good quality community integration”, avoid “the need for more expensive options” (p47). Moreover, that “any practical help needs to be based on supporting [people’s] individual aspirations to live independently and take part in society” (p47) does not account for people who may not want to live on their own. People’s aspirations will only be supported if they enter the inevitably financially restricted and institutionally defined framework of aspirations to live independently and take part in society.

Since total independence does not exist, then the term might presuppose that one is able to choose independently what and who one might want or need to depend on. Yet the NSF is based on assumptions about what independence is and how one may achieve it. As such, it therefore requires people to display a pre-programmed set of characteristics that form independence. The NSF requires people with long-term conditions to be dependent vis-à-vis their own independence. In the NSF, independence is seen as a key factor in people’s quality of life and the two terms are often used in the same sentence.

### c. Quality of life

The terms 'quality of life', 'well-being' or 'to lead a full life' are mentioned 36 times throughout the first chapters. Similarly to independence, they are not clearly defined anywhere in the document, despite the great confusion that exists in the quality of life literature (Cummins et al. 2002). However, the problematisation of life with a long-term neurological condition gives an indication of the assumptions of what a good quality of life may be. QR5, for example, is based on the following rationale:

People with long-term neurological conditions face many complex challenges in attempting to live as they would wish. At different times, they can experience physical, emotional, psychological and social difficulties. These can limit their ability to participate in society and can lead to social isolation, anxiety and depression (p35).

A good life is therefore one that does not know physical, emotional, psychological and social difficulties and people with long-term conditions are seen to potentially have all of these. Diagnosed bodies are problematised and framed in a way that highlights their limitations and assumes a causal relationship between those and quality of life.

In his Ministerial Foreword, John Reid, then Secretary of State for Health, states:

For many people living with conditions such as multiple sclerosis or Parkinson's disease, the main issue, *until science can find a cure*, is improving the quality of their lives, supporting them to manage their symptoms and live as independently as possible (p1, emphasis added).

The medical enterprise remains a curative one and quality of life is only the second best thing to be concerned about for health care professionals. The emphasis, in an era where long-term conditions pose an increasing challenge to health services (WHO 2002a), is still on cure and *quantity* of life. One has to be cured and can be seen as having a good quality of life only when brought back to a valued, 'normal' and independent state of being. Bodily possibilities have to be maintained, because life with limitations is framed negatively. The question of when a bodily (im)possibility becomes a limitation with an impact on quality of life is not addressed, but is assumed and framed by the discursively produced organ-ised, disease free and optimal body. The overwhelming assumption is that life with a disease is a 'bad' life and depicts an inherent rejection of the differently-functioning body, with possibilities as well as limitations. This is at odds with some of the

qualitative literature describing long-term conditions as overall sources of positive or even *transformational* experiences (Paterson et al. 1999; Lutz and Bowers 2005).

The fifth QR aims “to enable and support people with long-term neurological conditions to lead a full life in the community” (p35) through the provision of rehabilitation in the community. The assumption underlying this QR is that the only way for people with long-term conditions to lead a full life in their community is through the rehabilitation services provided to them. That rehabilitation activities are driven by a need to bring bodies to some optimal physical ability further reflects their assumed poor quality of life:

Community rehabilitation for people with long-term neurological conditions reduces the restrictions they experience in daily living, maintains their independence, and enables social participation (p35).

This is taken further in the sixth QR, which concerns itself with maintaining people’s occupational status. To return to work is qualified as “extremely important” (p39) for people, as they “often experience major restrictions in their ability to work” (p39). Vocational rehabilitation is crucial, in that “it can improve their quality of life and help them maintain their independence” (p40). This highlights and reinforces the utilitarian model of quality of life adopted throughout the NSF, which recommends that “a greater focus ... on helping people remain economically active” should be adopted (p40). A greater integration of health and other governmental, charitable institutions and rehabilitative activities will no doubt be of benefit to people with long-term conditions because it ceases to consider the organ-ised body in isolation of its social spaces. However, the assumption is that people with diseased bodies do not play a full and inclusive role in society. The social space occupied by a dis-eased and organ-ised body is striated in a way that understands positive social relationships as a sole asset of optimally functioning bodies.

Somewhat ironically, the greatest emphasis on quality of life throughout the document is in QR9, which concerns itself with palliative care. Specialised palliative care services are seen to have to “promote physical, psychosocial and spiritual well-being and emphasise quality of life and good symptom control” (p51). Quality of life becomes a crucial parameter when all curative or corrective activities are abandoned and death is near. Facing death as the ultimate challenge to medicine,

professionals can only offer to make the person comfortable within her body. There is a recognition that this may need to happen over some time:

Because of the protracted nature of long-term neurological conditions, people may need palliative care over an extended period of time to alleviate distressing symptoms and improve their quality of life (p51).

To palliate comes from the Latin word *palliāre*, which means to “cover up” (Collins English dictionary 2003). So at a late stage in the disease, all professionals can do is to cover up the effect of the malady on the body. Palliative care is also “cost effective in comparison with standard hospital and community care at the end of life” (p52). Disease is negative, linked with a bad quality of life, death and costs to society. It is oppositionally situated to health, which is linked to a good and independent life.

#### **d. Health and disease**

Information about the diagnosed condition is to be delivered gently at the time of diagnosis, through, for example, attendance to a ‘newly diagnosed’ course. Professionals announcing diagnoses are to be trained to break bad news in a sensitive way and the NSF encourages organisations to adopt a communication policy to this effect. These considerations, as well as much of the rest of the document, rest on the dichotomy between health as something inherently ‘good’ and disease as ‘bad’. This has been reflected in sociological research for decades. Shakespeare (1994) asserts:

The flesh of disabled people had historically, and within Judaeo-Christian theology especially, represented divine punishment for ancestral transgression. Furthermore, non-disabled people define themselves as ‘normal’ in opposition to disabled people who are not (1994: 292).

This can be generalised, since health as a wider notion has been viewed as a sign of virtue (Brandt and Rozin 1997). But healthy people are only healthy in relation to unwanted states of sickness. One would not exist without the other and the definition of the first is likely to change and evolve, as new diseases are discovered and defined. Health and illness are not necessarily ‘good’ or ‘bad’ or indeed rooted in the intrinsic nature of things, but are discursively produced categories with somewhat porous and imperfect application to a range of bodily sensations. One can only describe oneself as ‘healthy’ when one does not feel dis-eased, and whilst health may

only be a matter of 'good luck', illness is to be expected at some point in one's life (Williams 2000). Many people live with migraines, for example, but would describe themselves as healthy. Few people enjoy complete and uninterrupted health for any length of time. People may carry a diagnosis of multiple sclerosis or have had a heart attack and feel perfectly healthy. The two concepts are not only oppositionally situated to one another, but are defined through one another and, therefore, need the other to exist. To see them as antagonistic is to look at diagnostic categories from the point of view of an absolute health that does not exist. 'Health' is a text, a discourse that is promoted as financially advantageous for governments and as beneficial to subjects presumed healthy. As such, health colonises and squeezes out the contentious voices of the 'unhealthy'.

The fourth, fifth and sixth QRs put the emphasis on rehabilitation. To rehabilitate is to help (a person who has acquired a disability or addiction or who has just been released from prison) to readapt to society or a new job, as by vocational guidance, retraining or therapy (Collins English Dictionary 2003).

So to rehabilitate is to make someone able to live in society again. The amalgamation in the term's definition between disabilities, the treatment of drug addiction and the end of a prison sentence, is revealing. This sits in a functionalist paradigm, in which impaired bodies should be rehabilitated too. When this is not possible, they are expected to remain in a dependency role, out of a society of functioning and working bodies (Lutz and Bowers 2003). What this presupposes is an ingrained rejection of a body that is different, disorganised or chaotic and may not 'work' as others. The body needs to be re-trained through massage or exercise to function optimally. This re-organisation of the body affects the social spaces it occupies, in that a rehabilitated body is deemed to fit better in society. In addition,

Early rehabilitation reduces the risk of developing preventable secondary complications... Continued co-ordinated multidisciplinary rehabilitation in the community improves long-term outcomes (p31).

These secondary preventable complications and long-term outcomes are professionally defined and problematised as things to be corrected or improved. In the absence of a possible cure, health care professions focus on what can be corrected and brought nearer to the ideal of the optimally functioning body with organs. Lupton et al. (1995) note how discourses of risk,



including the current obsession with screening and the early detection of disease, rely upon the inspiring of anxiety, vulnerability and concern about hidden illness or disease lying in wait (1995:105).

‘Complications’ and ‘long-term outcomes’ become the tools to inspire concern and encourage compliance. On the other hand, they are the new acute conditions to be treated and corrected within a chronicity that otherwise disempowers professionals. Gadamer asserts: “health does not actually present itself to us” (1996: 107) but rather manifests itself precisely by virtue of escaping our attention. Morris reinforces this by defining health as a moment in time, rather than a concept:

it describes a state that precedes illness, so that we recognise *when* we have lost it, even if we can’t say exactly *what* we have lost (1998: 247, emphasises in the original text).

By privileging the development of care plans and regular monitoring, the NSF attempts to colonise this moment preceding a complication, a flare up or a relapse within an existing diagnosis. In that, people who may feel well are constantly reminded of the impermanence of their status, given the diagnosis they have been attributed. Regular checks and monitoring place the body on a conceptual scale of functioning, so that complications can be pre-empted. While this is likely to be welcomed by some people in some circumstances, the choice of the timing and level of professional intervention appears limited. The control over bodily tribulations is exerted through a control of processes through time and space, which is explored in the following paragraphs.

#### **e. Time and space**

Time in the NSF is organised in diagnostic, treatment and rehabilitation phases, and is structured as such in order to prevent future bodily (mis)happenings. The aim of the second QR is to

ensure that people presenting with neurological symptoms or a neurological condition receive the correct diagnosis and appropriate treatment *as soon as possible* (p24 emphasis added).

The notions of time and space are crucial to this QR, as speed of diagnosis and treatment is paramount and the location of treatment is to be as close to the person’s home as possible. This is based on evidence that shows that “people have better health outcomes and improved quality of life when they have prompt access to expert

advice” (p24). Yet the nature of some neurological conditions, such as multiple sclerosis, means that people may live with tingling sensations in their extremities, for example, for years before seeking medical advice. Often it is after a first relapse, or a worsening of the symptoms, that people access their general practitioner, who will then base their initial assessment on the repetition or duration of the symptoms. So in the case of a slowly evolving condition with diffuse symptoms, prompt diagnosis is impossible. The disease develops over time, unseen from the professional eye and becomes an intimate part of the person, before she enters the patient territory through diagnosis. In order to diagnose and to treat, medical science makes invisible body spaces visible to produce hard evidence of an illness (Corbin 2003). It emphasises the organ-isation of the body and its own expertise. In the case of diffuse symptoms, a care plan may be established to organise, plan and co-ordinate pre-diagnostic testing:

Some conditions will need further investigations before a final diagnosis can be made. In this situation, a care plan can be agreed with the person for their investigations at the same time as booking appointments for the tests. All tests need to be completed as soon as possible and the person seen again by the neurologist without delay (p25).

Investigations and tests are planned so that unclear symptoms can be met with clearly defined and organised procedures. This regimentation of the process of diagnosis instates the medical discourse that the person enters in presenting with symptoms. At this stage the body is organ-ised and inside spaces investigated. The uncertainty of unexplained symptoms is faced with the certainty of the care plan and its investigatory technologies.

Early diagnosis leads to “earlier treatment and effective management... slow the progression of the disease and in some cases, may even prevent death” (p24). The disease has to be detected early, so that control can be exerted as soon as possible on its progression. Underpinning this process is a physio-pathological discourse, in which the malfunction has to be scientifically established, in order to improve the malfunctioning body and keep it alive. There is a time sequence during which lived sensations give way to technological ascertainment. During that time the person becomes a body in need of examination and personal time becomes regimented in technological procedures.

Once the condition is diagnosed, “the process of multidisciplinary assessment and care planning needs to begin as soon as it is required” (p25). Once sensations have been replaced by the concreteness of a bodily process gone wrong, the person becomes a patient. Treatment regimens are to be regularly reviewed in order to assess “how [people] are taking their medicine, whether they are tolerating them and the impact of medicines on their conditions and on other aspects of their lives” (p26). The regularity of reviews encourages compliance in between direct medical contacts. This regularity of timing reduces the physical and conceptual spaces between the dys-organ-ised body and organised professional bodies.

Rehabilitation programmes are put in place without delay and made accessible to the patient in order to meet her changing needs. “For some people, planned re-admissions to the inpatient unit over a number of years may be the most appropriate way of meeting their changing needs” (p32). The emphasis is on ongoing or regular contacts with health professionals, so that the body can be closely monitored.

There is little space in this organisation for management strategies developed over the time of lived experience and little space is left for them to develop once the NSF is implemented. Contacts occur on a regular basis, which minimises the space left for individual agency. The notions of needs and risks are professionally defined, assessed and addressed. The NSF highlights the fact that people may have developed a degree of expertise in managing their condition. However, the emphasis on planned technological ascertainment of bodily sensations, as well as prompt access to expert advice and early treatment, has the effect that the medical discourse moulds and frames lived experience from the very early stages. The intensity and regularity of professional contact recommended under the NSF is likely to greatly shape this expertise for future generations of people with long-term conditions. Gained knowledge will be skewed, so that the influence of instinctive, felt and lived bodily experience will be diminished and space made for a technologically defined one.

Knights and Yakhlef (2005) examine time in terms of social relations and distinguish between ‘Reification’, or the absence of social engagement, and ‘Participation’ or its presence. They state:

Reification, or the treatment of time as if it were independent of human construction, tends to involve unilinear discourses of time structured around a preoccupation with the self. Participation, where time is tied to the contexts in which it is entrenched, by contrast, is associated with a non-linear temporal discourse, revolving around 'time and the "other"' (Levinas 1987), or time for the other (Knights and Yakhlef 2005: 283-284).

They describe how for managers and organisations, time is problematic and a target of control, management and manipulation. Using these concepts, the patient can be seen as reified in terms of his risk profile. The long-standing relationship between the family doctor and the person, in which the doctor would have been assessing risk through a knowledge of the person, their family, occupation, interests and social engagements and surroundings, is long gone. This is replaced by series of techniques and technological advances such as early diagnosis through MRI scans and the care plan. Impersonal techniques for assessing risk, such as validated measures of functional status, displace the time-intensive interpersonal methods of the past, which were always prone to failure, because of their over-reliance on personal judgement.

Pinder et al. (2005) trace the intellectual origins of care pathways as organisational tools back to the Enlightenment's social engineering model of society, with its twin belief in rationality and constant improvement. Care plans and pathways result from a drive to standardise professional performance and to create a more rule-based, auditable practice, less reliant on professional discretion. The use of care plans from diagnosis to death constitutes a variant on what Foucault (1977) referred to as the 'Panopticon', where the mere possibility of total surveillance is designed to generate considerable bodily discipline. The care plan from diagnosis to death is constructed on the basis of a regular time conception of the subject, who is seen as having a predictable, progressing though irregular disease trajectory. It is also based on an inherent lack of trust in the felt experience of the illness and is a reification that detemporalises and deterritorialises the interaction between patient and health professional. There is no need to define each situation anew in its minute details, since the pattern of action is predetermined and serves as a guideline for future happenings. Care plans standardise interactions between patients and professionals in time, in that each party is clearly assigned tasks and duties (Pinder et al. 2005). Tests and reviews are goal oriented and become the frame for interpersonal

relationships. This strict planning and organisation of institutional time in personal spaces appears inconsistent with the discourses of patient centredness and empowerment used in policy documents in recent years.

**f. Patient centredness and empowerment**

The aim of the first QR is to

Support people with long-term neurological conditions in managing their conditions, maintaining independence and achieving the best possible quality of life through an integrated process of education, information sharing, assessment, care planning and service delivery (p19).

Education, information sharing, assessment and the planning of care are all seen to guarantee a person-centred service, which in turn will improve people's management of their own condition, their independence and ultimately, their quality of life. Rogers et al. (2005), in their exploration of the limits of patient centredness, define the concept as follow:

Patient centredness is predicated on an understanding of the patient as a unique human being and refers to a style of doctor-patient encounter characterized by responsiveness to patient needs and preferences using the patient's knowledge to *guide actively the interaction and information giving*, and shared decision making (2005: 226; emphasis added).

In contrast to this in QR1, education, assessment, care planning and delivery are all done to people, while 'information sharing' is the only expression of a dialectical relationship.

Once multidisciplinary assessments are completed, an integrated care planning and review system is put in place. During this process, the emphasis is on person centredness and on the recognition that people's "needs will change over time" (p20). The care plan is to be developed and agreed with the person, and they *own* it, with relevant professionals reviewing it at regular intervals. The sense of this ownership begs questioning, for when one owns something, they are free to keep it or throw it away, use it or transform it, without having to ask anyone else's consent. This is not the case for the care plan, since changes have to be negotiated and needs re-assessed professionally at regular intervals: "regular monitoring and review

processes are needed” (p20). In contrast to this, Paterson et al. (2002) found that in their study of self-care decision-making in long-term illness, people with MS “emphasised that they were more likely than “strangers, like the doctor” to know “what works”” (2002: 71). They conclude that

practitioners cannot assume a commonality in the experience of self-care decision-making, and that therefore common approaches to education will not be equally successful in every case (2002: 71).

Van Kleffens et al. (2004) studied the concept of patient autonomy with regards to decision-making in the refusal of cancer treatment. Patients in their study perceived medical information as one in an array of influencing factors for their decision-making. They highlight the importance of the patients’ personal values, emotions, beliefs and attitudes towards life, suffering and death in their decision-making process. Participants in this study stated that they could not feel free to choose, when an option *not* to treat was not put to them. When they had a choice, it was between different treatment options and therefore their choice and sense of autonomy were jeopardised. In the NSF, treatments like rehabilitation are put forward as standard practice and regular reviews are planned, in order to re-assess needs. In other words, people’s choices are limited to different and possibly evolving treatment options, but non-treatment or the use for alternative therapies, for example, are not put forward as possible choices.

The last section of the first QR focuses on “information, advice, education and support” (p21). This recognises that people who live with a condition for years, often develop a degree of expertise in its management, which can “help professionals to support them” (p21). In addition to this knowledge gained in the lived experience, people will be able to access information in different formats and at different times during their disease trajectory. “Providing good information and education benefits the person by improving opportunities for choice and levels of independence and can reduce consultation rates” (p21). The information that is ‘good’ originates from one, reputable source inscribed in the medical discourse and resulting opportunities for choices are therefore effectively limited. Instead, Koch et al. (2004) demonstrate how people are able to achieve

a level of self agency that does not rely on health care professionals taking the lead role in management... nor does it necessarily require us

to provide 'off the shelf' self-management education about how we think that people ought to cope (2004: 490).

QR2 puts the emphasis on early diagnosis and treatment, but the document states that "around 50% of medicines for long-term conditions are not taken as prescribed" (p25). The emphasis is therefore on educating in order to maximise compliance. However, as well as providing information, professionals are to "discuss the person's preferences with them and reach a shared agreement about the proposed form of treatment" (p25). In a text that wants itself patient centred, the expectation is that of passivity and compliance with the medical discourse. Pinder et al. (2005) describe care pathways as based on a biomedical and essentialist model of the patient, which define their situation by their impairments. The choices on option are offered within the parameters of the biomedical model of health care. This is echoed in Roger et al.'s (2005) study, in which they found evidence that self-management was interpreted by professionals as referring to compliance to medical instructions. In their study, self-management equated with compliance with medication in relation to a medically defined notion of a flare-up. This differed from the patient's definition, which was more refined, since they could distinguish between "a mild flare-up, a major flare-up or just a bit of a flare-up" (2005: 232), and used management techniques other than medication. Professionals generally marginalised patients' experiential self-management strategies. In this study, the information shared during the encounter with a professional revolved around medication use and minimised the significance of the person's expertise in the management of the disease. Processes of shared decision-making were therefore generally superficial. The NSF recommends regular reviews of the agreed treatment choice, and "the reviewers can agree adjusting medication with the person" (p 26). Verification is made of the person's level of compliance and agreement is reached over future medication regimen. This is at odds with the claims about people's level of expertise about their own condition found elsewhere in the document (QR1). Koch et al. (2004) assert that "the 'self' in self-management has been ignored and the person has been objectified as 'the patient'" (2004: 485). While giving plenty of guidance, medical management criteria, as set out in the NSF, give little relevance to alternative ways of living with a long-term condition.

Another emphasis in QR4 and throughout the document is placed upon integrated and multidisciplinary work to best address the complex needs of people with neurological conditions. A little attention ought to be paid to the word *disciplinary*, as its dual meaning may be of signification. Disciplinary means both “relating to a branch of learning”, and “promoting, or used for discipline”. Multidisciplinary, on the other hand, means “relating to the study of one topic, involving several subject disciplines” (Collins English Dictionary 2003). In the case of the document studied here, the topic is the body, which is studied through the lenses of several disciplines and which is disciplined in its use and response to treatment. Multi-disciplinarity therefore, reflects both the multitude of disciplinary outlooks on the body, and the array of disciplinary techniques embodied in the care plan.

**g. The NSF as a territorialising device**

The NSF has been presented as the first document of this type with such a strong focus on service user perspectives (Turner-Stokes et al. 2006). However, the discourses highlighted in it contribute to a particular medical territorialisation of the ‘diseased’ body. In this, it highlights a conceptualisation of the subject as ‘trapped’ in a dysfunctional body and having to adapt to the limitations this engenders (Williams 2000). The NSF plans and co-ordinates care in a way that extends the medical discourse from the organ-ised body to its immediate social environment. As such, it promotes multi and inter-disciplinarity, but it does not concern itself much with the wider social forces that permeate how the body is experienced both by the person and his immediate social environment. The NSF focuses on the effect of the disease on the body, both in its internal and external social spaces, and proposes best ways of organising and planning care.

The NSF introduces a series of measures, seen here as technological systems, which aim to control the disease progression. There is a paradox between manifestations of medical technology as an enabling-through-knowing device and the inevitable knowledge / power inequalities it implies. Intervention is justified as a remedy for personal distress and its potential for increased quality of life. However, the application of technological control also perpetuates a view of people as bodies with



dysfunctional organs, which devalues lived experience to passive feedback on technological success. Patients' empowerment and involvement in their own care remains largely dictated by the professional agenda. Powel and Biggs (2004), in conducting a Foucauldian analysis of ageing, assert that: "'a healthy old age' signifies that one has lived a 'moral life'... by comparison, becoming unhealthy approximates being undeserving" (2004: 20). One becomes unhealthy because the proper steps of self-care have not been taken in the past. The NSF introduces a series of techniques of control, aimed at enticing patients to be assiduous in taking their medication or following their rehabilitation regimen. Outside of these guidelines for living with a long-term condition, people may become 'bad', undeserving and responsible for what may happen to their body in the future.

Care pathways have been described as tools to identify 'gaps' in health care provision and to remove 'bottlenecks' to smoothen the passage of patients through the system (Pinder et al. 2005). Similarly, the care plan establishes, in a neat and ordered manner, the steps to be taken for the care of people with long-term conditions, and puts the emphasis on prompt professional response to patient need. It runs the risk, however, of reducing care through over-rationalising. Care plans and pathways respond to organisational and political imperatives of cost effectiveness and efficiency, which run the risk of silencing the patient and his experiences, beliefs and particular needs. There is a potential for it to reflect and reproduce the very tensions between patient centredness and organisational or political imperatives that it strives to resolve.

The care plan has the potential to become a mobilising metaphor, opening up space to truly negotiated care. Practitioners should, however, become aware of the assumptive language underpinning it, for such a possibility to be realised. Bodies need diagnosis, treatment and professional responsiveness. But their potential of becoming without organs, or with organs but out with the medical discourse, needs to be acknowledged.

## **Certainty and Uncertainty / risk**

Adams (2005) exposes the relativity of the notion of risk in the aftermath of the London bombings in July 2005:

In Britain on an average day nine people die and over 800 are injured in road accidents. The mangled metal, the pain of the victims, and the grief of families and friends, one might suppose, are similar in both cases. Measured in terms of life and limb, 7/7 represented six days of death on the road. But thousands do not gather weekly in Trafalgar square to manifest their collective concern.

Adams (2005) argues that the way in which people better accept certain levels of risk varies with the perceived level of control that they may be able to exercise over it. He distinguishes the voluntary risk taken by the mountain climber from that undertaken by the driver in London during rush hour. The sense of control that drivers feel over their fates appears to encourage a high level of tolerance of the risks involved. Uncontrollable risks, such as natural disasters, attract mixed reactions, whereas people generally display little tolerance for imposed risks such as those associated with mobile phone masts. The least tolerated risks are those voluntarily imposed on people, and this is exacerbated when the intention is malignant, as with terrorist acts (Adams 2005). These reactions to risk are all situated on an individual level and all translate to a health care setting. We are, generally, rather tolerant of the risk we run of developing a disease that may be lurking within our body, as we have very little control over its development. On the other hand, we tolerate much less the risk imposed on us by cigarette or fast food manufacturers, which is motivated by profit. Finally the type of risk imposed on us by malevolent doctors, for example, is one making the headlines and causing outrage. Yet statistically, we are much more likely to develop, at some point in our life, a long-term or life threatening condition than discovering that our family doctor is a serial killer. As Petersen and Lupton (1996) state, "risks are sociocultural constructs; are always political in their construction, use and effects; and inevitably include moral judgements of blame" (1996: 18).

Althaus (2005) provides an account of how risk is perceived by different disciplinary traditions. She highlights how, linguistically, the distinction between the concepts of risks and uncertainty has been lost. In contemporary societies, risk tends to have a negative connotation and its understanding tends to be dominated by quantitative thinking (Althaus 2005).

Reith (2004) deconstructs the notion of risk, demonstrating that it is the reification of the probability that something will happen in the future, the reification of potential danger. The term 'risk' was first used in the middle of the seventeenth century and brought time and uncertainty into a quantifiable relation. The practice of insurance as a means of shielding against uncertainty and protecting the individual against these newly predictable events, developed almost immediately. Organisations are based on the notion of risk as a real phenomenon and on the assumption that it can be experienced, produced or measured (Rose 2001; Adam 2006). However, as such, 'risk' is not something that exists, but merely an approximate measurement of probable outcomes. It cannot be experienced, since it is framed by its relation to an unknown future and is defined through this temporality. Reith asserts:

independently of success or failure, [the notion of risk] provides a justifiable guide for behaviour. Although it cannot make the future predictable or the world certain, it can create the means *for acting as though it were* (2004: 396, emphasis in the original text).

This is particularly the case for science and medicine, which tend to understand risk as an objective reality that can be measured and over which one can exert some control. According to this, the binary between the 'normal' and the 'pathological' is now blurred in favour of an administration of risk, as there are increasingly more sophisticated ways of identifying and preventatively or prophylactically intervening on 'at risk' groups (Rose 2001). The calculation of risk brings the uncertain future into the present domain of individual agency and forms the basis of most health promoting or disease preventing messages. Clarke et al. (2006) state:

Risk and surveillance ... are aspects of biomedicalisation that ... implicate each of us *and* whole populations through construction of risk factors, elaborated daily life techniques of self-surveillance, and the management of complicated regimens around risk and chronic conditions (2006: 172).

It derives from this that risk discourse in public health 'pathologises' and 'moralises' life, in that according to this discourse, when people choose to ignore health risks they place themselves in danger of illness, impairment and disease (Rose 2001; Althaus 2005; Clarke et al. 2006). In this case, the symbolic relationship between sin and risk is reversed in that, for example, obese people who are deemed 'at risk' become sinners, because of their apparent voluntary courting of risk (Lupton 1995; Williams 2006). Lupton (1995) questions the value of screening tests as predictors of individual risk. In a similar vein, Armstrong (2001) describes how the medical discourse has created a world "in which everything is normal and at the same time precariously abnormal" (2001: 148). This is because risk factors open up a space for future illness potential, rather than existing symptoms pointing at some hidden pathological truth.

Later corroborated by Althaus (2005) and Clarke et al. (2006), Armstrong (2001) also describes how Surveillance Medicine turns increasingly to the extracorporeal space often described as 'lifestyle' to identify the precursors of future illness. The NSF for Long-Term Conditions (DoH 2005) illustrates this, in widening the scope of the medical discourse from the dys-organ-ised body to its place in a physical and social environment. This extracorporeal focus is also illustrated in television programmes such as *You Are What You Eat*, where obese people are described as time-bombs of high blood pressure, coronary heart diseases or diabetes. Symptoms, signs, illnesses and lifestyles become indicators for other potential symptoms, signs and illnesses. People's lives become striated in their present and projected bodily signs, through the notion of risk. From this, Armstrong (2001) derives that: "the problem is less illness per se but the semi-pathological pre-illness at risk state" (2001: 149). Uncertainty is seen as a threat to quality of life, because life itself has to be predictable and certain.

It follows that risk discourse in the context of public health relies upon awakening notions of anxiety and concern about the hidden illnesses lying in wait in the body (Lupton et al. 1995). Lupton (1995) shows how the experience of taking a diagnostic test may indeed be unsettling.

Those individuals whose anxiety is aroused by having a test will not always be reassured by the result, and may find the experience frightening or degrading, placing them in a liminal state where they are neither 'ill' nor 'well' (1995: 99).

The organisation of screening programmes, which aim for early detection of the disease process so that it may be reversed or at least controlled, is thought to introduce certainty in the lives of people deemed at risk. Yet the prospect of knowing what may lurk in their body, the prospect of certainty, confronts people with the possibility of disease. This uncertainty, which can only be highlighted technologically, asserts the medical authority because of the organisation and certainty that they oppose to it. This certainty of diagnostic category and technological knowledge only exists in the face of people's increased awareness of their vulnerability and the uncertainty of future bodily happenings.

In the emerging 'risk societies' (Beck 1992), 'healthy' bodies, rather than those who are 'sick' or 'diseased', are indeed increasingly becoming the sites of medical attention and interventions. In the NSF for Long-Term Conditions (DoH 2005), diagnosis is conceptualised as a process, rather than an event, which is framed by a plan of activity similar to that which leads treatment and rehabilitation. Within late modernity, increasing onus is being placed upon individuals to take responsibility for all aspects of their present and future lives (Lawton

2002; Althaus 2005; Clarke et al. 2006). Indeed, whereas historically disease and its causation were understood in fatalistic terms, within the late-modern Western societies, responsibility for health and its maintenance is set firmly within the hands of individuals.

Lawton asserts:

the presence, or absence, of 'health consciousness', 'morbidity consciousness' and 'death consciousness' often appear to have a direct bearing on people's motivation to adopt behaviours aimed explicitly at lessening their risk of future ill-health (2002: 715).

Lawton's study focused on the extent to which people actively thought about future eventualities of ill-health and death and how these perceptions shaped present health behaviours. She identified that embodied experiences of long-term ill-health had direct impacts on people's perceptions of further morbidities and mortality, and as a result on their health-seeking or health-preserving behaviours. These, as Adams (2005) might have led us to believe, tended to be reactive rather than proactive. The bodily effects of long-term disease brought about a reconceptualisation of self as being "inherently vulnerable and contingent" (Lawton 2002: 726). Just as a driver who has narrowly escaped a road accident may then become particularly cautious and attentive, illness brings about an awareness of the actual statistical risk of developing a disease. Whilst Lawton's study has relevance for health promotion strategies, which she highlights in her article, it also has repercussions on the way in which people with long-term conditions are perceived. People's feelings of vulnerability and contingency in long-term condition are recognised in medical discourses as fear of uncertainty. This is addressed through increased control (Althaus 2005) and an emphasis on compliance with treatment regimens. In other words, vulnerability and contingency are addressed through organisation and striation. The ACTIVE programme is inscribed in such a risk paradigm, as people exercise to prevent further bodily deconditioning.

Knights and Yakhlef (2005) introduce the notion of contracts as reifying devices that are expected to stabilise individuals in time and space, by placing them in 'fixed' categories and boxes. If one conceptualises the use of the care plan as advocated by the NSF as a moral or social contract, it derives that it frames and stabilises the experience of long-term illness in the avoidance of future bodily happenings. Cost and control driven policies pursue strategies of organisation designed to reduce time to a rigid reified image of itself. Accordingly, Lupton et al. assert:

Risk, as the concept is used in public health, may be regarded as having less to do with the nature of 'danger' than the ideological purposes to which concerns about risk may be put (1995: 105).

Time in long-term illness is apprehended as linear and organisable, so that the future can be predicted and, as much as possible, controlled. Events in the future are regarded as caused by occurrences of the past, from which they emerge in a straightforward and linear progression.

## **Care defragmentation in the relapse clinic**

### **a. Service C**

The relapse clinic is part of a highly specialised neuroscience Trust in the UK. Its mission is “to maximise the independence and improve the health of people with neurological injury, illness, disability or pain” (Annual report 2005), through the provision of a comprehensive range of neuroscience services. It participates actively in the political landscape of the NHS, by advising on the shape and content of such documents as the NSF for Long-Term Conditions (DoH 2005). The Trust presents itself as a powerful, dynamic and questioning environment for professional practice, where scientific evidence serves as a *sine qua non* for service development and evaluation. For example, the relapse clinic was set up following a randomised controlled trial evaluating the benefits of multidisciplinary management combined with intravenous steroids for relapse (Craig et al. 2003). The results indicated clear benefits to the patients, and spurred the research physiotherapist to set up the weekly clinic evaluated as part of this project. The format allowed patients to be seen more rapidly after their relapse and all symptoms to be addressed in one visit, followed up by relevant professional(s) according to identified needs. The process was therefore designed as a faster and more efficient process to address relapses.

This introduction sets the scene to the evaluation of service C: the setting is a prestigious medical institution and the premises to the service development are that relapses have a negative impact on people’s life and that a multidisciplinary approach to relapse management is particularly efficient. These are the two aspects of the service that will be examined in more detail in this analysis.

### **b. A ‘defragmentation’ of the system of care**

An analogy with the operating system of a computer can be used to describe the effect of the relapse clinic on the running of the service as a whole. In the normal day to day running of a computer, as files are being deleted and added to the system,

others are being split and the pieces scattered over different areas of the disk. This affects the overall performance of the computer, since the operating system takes longer to gain access and read the scattered pieces. Likewise, prior to the relapse clinic it could take months to get an appointment with the consultant neurologist, who would then send referring letters to appropriate colleagues. This whole process was not as efficient as it could have been:

In the past it's been like you go and see the neurologist and then in a couple of weeks time you get a letter and that goes from that person and that goes [to another] person then goes to someone else... And over a period of like two months, you can see everyone... it's a long paper chase... the physio to the OT, to the nurse to the neurologist (Paul).

One of the implications of this was the time it took to be seen by a specialist:

[prior to the relapse clinic] it was time wasting really, by the time I'd phoned the doctor, got an appointment... Got the steroids... Waited and seen if they made any difference, and then got onto the people I should've got onto originally (Margaret).

This could mean that the acute episode they were going through, the relapse, was not treated as such.

The doctors are very busy and they're always booked up with appointments, so if you've got an appointment say in six months time and you have a relapse, you can't wait that number of months (Alan).

Another participant described his experience as feeling “pushed from pillar to post” (Paul). This could be in relation to time, but also to disciplinary specialties, as is illustrated in the following quote by a professional.

[working in the relapse clinic] just gives you the click that you know, this is a whole person that we're talking about really and not a box bit, not the bladder bit or the walking bit or the eye bit you know, it's what that problem is causing... I think that ... takes it away from just being the medical problem to them being the person and that's got to be a bonus, that's a learning curve for us all (Philippa).

This professional describes how engaging in multidisciplinary work has enabled her to stop looking at patients in fragmentary terms. Professionals who are specialists in the care of an organ are brought together like a professional body of organs. This enables them to appreciate the body as a whole entity and the effects of the pathology on its immediate physical and social environment, as recommended in the NSF (DoH 2005). A patient corroborated this, contrasting the relapse clinic with previous experiences:



[the professionals in the relapse clinic] could feel we are people, we are not numbers, and I think again in the past I hadn't been treated or felt as though I had been treated as a number rather than a person, you actually become people (Angela).

The disk defragmenter of an operating system moves the pieces of each file to one location on the disk, so that each occupies a single space and that related files are placed contiguously on the disk drive. As a result, the system can gain easy access to files and folders and save new ones more efficiently. The analogy is that by treating patients by dysfunctional organ or through their General Practitioner, some aspects of their symptoms were previously left unaddressed, leaving gaps in the care people received, where they had to just 'get on with it' and took longer to recover. One participant described how she was amazed when, following the relapse clinic, she was referred to an optometrist for her double vision. She had had the symptom intermittently for nearly two decades during which it had been left unaddressed. "But they seem to go to any lengths to try and find remedies for, you know, other parts of your condition" (Anne). This is a reflection of the previous fragmentation of the body by disciplinary specialties, in which 'other parts of the condition' did not fit. With the relapse clinic, every symptom is considered using a super-specialist approach, enabling a defragmentation of the system of care from which the patient, or computer-user to extend the analogy, is seen to benefit. So the service user faces a faster, smoother, more comprehensive and efficient system of care. This reflects the pervasiveness of a consumerist discourse in both patients' and professionals' comments, an aspect explored in the following paragraphs. Time is saved where it was previously lost in bureaucratic exercises and the conceptual space between symptoms, body parts and impairments is reduced in defragmentation.

**c. A positive experience for the patient**

All patients participating in the study described the relapse clinic as a positive experience. For some, this was as a direct result of the defragmentation process.

And you see them altogether now so it's better because it saves your energy and power basically [rather than] have to tell everyone the same things (Grace).

Like in a computer, the service defragmentation saves the user's 'energy and power'. The use of these terms reflects the culture of efficiency in which the relapse clinic has been set up and in which patients live. The service is more efficient and faster to help people get back to their pre-relapse state. This efficiency meets a user demand to be seen while unwell:

The fact that you ... get to see somebody quickly. They see you while you're not right. It does not happen that often, because a lot of the time when you have a relapse you just know what it is and you just then get on with things. But if it gets really bad, it's good to see somebody (Steve).

This suggests that, previously, the time constraints of the appointment system meant that patients had to fit within professionals' busy schedules that were often out of synch with their bodily experiences. With relapses, people move in and out of impairments from which the body heals itself. Steve's quote suggests that there are degrees of impairments, with some of them requiring professional help.

People described the relaxed atmosphere in the clinic, in which there seemed to be no pressure on time. "You're not rushed, you know. There's no time limit" (Anne). Communication between professionals was described as first hand and immediate, in contrast with previous episodes.

There's a lot of interaction. And they can sit and talk. They don't need to sit down and do dictating onto the letters ... all the health professionals are there ... and they're concentrating on me (Paul).

Following defragmentation, professionals spend less time dealing with administrating the care and more time in interaction with the patient. This time allocated to communication was described as a crucial element of the clinic:

You come out of [the relapse clinic], OK, you've got a disability and you've had a relapse so your body isn't as well as it should be, but you come out feeling on top because you've asked all your questions, they've been friendly with you ... They'll give you as much time as you need (Alan).

### *The relapse clinic and timeliness in the illness trajectory*

A natural healing process occurs in the body after a relapse. "It's a question of letting it go through its natural course and that's what I've come to realise now" (Paul). For patients, the role of the relapse clinic is to help and speed up this natural healing process, when the impairments they face are particularly extended. Another

participant also commented on this, emphasising the little control he has over his body and that no matter how much physical support or treatment, “I’ve got to get myself back over there” by, for example, resting and giving his body a chance to heal... “But support is the main thing” (John). Support from professionals is seen as crucial, so that the person does not feel on her own with a body over which she has so little control.

The relapse is likened to a journey in an unpleasant and disempowering place of bodily disharmony and impairments, from which the body comes back in time. Empathy and moral support are crucial to make this return journey a little smoother. The relapse clinic offers this empathic dimension in a consumer friendly way of responsiveness and efficiency. So although the aim of the relapse clinic is short term and cure-based (“They fixed me up” – Steve), the experience of it reflects a caring environment. “There’s the question of empathy... if someone has a little bit of an understanding, it goes a long way” (Paul). Paul’s experience was reflected in many other participants’ interviews:

I actually felt better for it, the fact that there was so many people that were actually interested in and actually taking an interest you see as a person you know, so many people were interested in the actual illness itself you know. Sharing is a very important factor... (Angela).

Pervasive in the transcripts is a sense of loneliness in facing the peaks and troughs of the disease. The relapse clinic goes some way to counter that, in being there when people need it most, “it helped my mind... knowing that there’s something there and not being cut off, things aren’t just fading away from me” (Helen), by not imposing any time constraints and ‘taking an interest’ in the patient’s story. This comes in contrast to the figure of the busy professional who may treat physical symptoms, but has no time for the person. “It takes a lot of the worries and stress out of it” (Anne). Professionals corroborated this: “It’s certainly more relaxed because there are only sort of 4 or 5 patients in the clinic as opposed to ..... the other clinics we were running at about 20 or 25 patients” (Quentin). The relapse clinic gives more time to both patients and professionals to interact, and this is accepted as a crucial element of the clinic. The time-space of the consultations enables the dys-organ-ised body to be apprehended emphatically as a whole entity.

For patients, an important aspect of the relapse clinic is its capacity to act as an insurance against the possibility of further relapses. Like an insurance policy, it cannot replace what has been lost, but as well as speeding the recovery and offering time and empathy, it can make the occurrence of further relapses less daunting.

This goes back to the uncertain nature of MS and how this affects people in their life as a whole... It is only when you get a relapse that you think about [MS]... when you are restricted in some way. But knowing that you do not have to worry because there is somebody out there who can help....I think that makes you feel able to do more. So you are not sort of sitting worrying at home thinking, 'I can't do that'. Because if something did go wrong, they are just a phone call away (Steve).

When asked about the successful elements of the relapse clinic and their effects on quality of life, it was on physical symptoms that professionals focused, rather than this reassurance.

The patient experience is enhanced and I think that has to be a bonus as far as quality of life is concerned ..... because you are addressing you know, symptoms that often went unaddressed like double vision for example ... correcting their double vision which would previously have just been allowed to sort of settle spontaneously, you must be, you know, over the short term at least improving their quality of life during the experience of the relapse (Quentin).

So there seems to be a gap between what professionals think they are providing, which is based in the curing and outcome-focused culture within which they practice, and what the patient perceives to be provided, which is based in a caring paradigm.

#### **d. Temporal fragmentation**

People are no longer seen through their dys-organ-ised body parts, but are selected at a certain phase in their illness trajectory. The following extract from the interview of a member of the multidisciplinary team illustrates and explains this.

A lot of people say that they have relapses on the telephone ... and they haven't actually had relapses... So it does raise issues about how you classify relapses ... what you use to define a relapse ... even GPs will say things but they'll say things in that situation to try and get the patient into the clinic and stuff like that. So we've had quite a few problems. Sometimes the people not having MS coming into the clinic, which is a bit annoying... it's not hired as anything else but an MS relapse clinic! So we've had at least two people I know who haven't got MS being got in... and we've also had one or two doubtful

diagnosis which we've really objected to having because the clinic isn't a forum to discuss diagnosis... I'm not there as an opinion on an MS patient ... the patient should be seen by the consultant... as a 'new diagnosis'. So that's not our role. You had to vet it and restrict people who had been allowed to put people on it because sometimes people were ... they were just using it as a way, like everything in the NHS, of getting rid of a difficult person. Stop them moaning by dumping them on our clinic... well it's a waste of time for everyone really.... we wanted to put up a big sign saying 'This is an MS relapse clinic, if you come through here you've got MS, don't come through here if you don't know you've got MS!' (Richard).

What this extract highlights is a temporal fragmentation of people's life. Only people with an established diagnosis and who have a relapse, are seen within the clinic. This highlights the limitation of our study, which included only people who had been through the relapse clinic. It may be that people who 'moan and groan' at their GP's would have had a different outlook.

In the relapse clinic, professionals have had to learn to work together and stop looking at people like a series of symptomatic boxes, but rather as whole bodies. What has happened in this process is the creation of a different type of fragmentation. People's lives are broken down by temporal stages in their illness trajectory, between 'new diagnosis', 'not relapse' and 'relapse'. People with a progressive form of MS present a different challenge to professionals, since there is no room for a "front management" (Safiya). So although MS is a long-term condition, the relapse clinic selects people on a "clear-cut story" (Safiya), which reflects and informs professionals' definition of a relapse.

[The relapse clinic is] an ideal, a good platform to start getting information on people who have relapses and the longer term picture of what happens and how relapses relate to the condition and progression (Richard).

In that process, MS management is organised through a series of discrete and precisely defined acute episodes. In this, it is possible to articulate the professional viewpoint in terms of the consumerist culture in which they operate. Life has to be predictable and when it is not, the relapse clinic offers insurance against adverse episodes, in order to enable those people carefully selected to get back to their pre-disease bodily state as soon as possible.

**e. Relapses and their impact on quality of life**

When I met John, he spoke a lot about the effect MS had on his life. He contrasted it to the way in which someone who might get an acute health problem either recovers from it, or adjusts to it:

With MS ... you're up and down, like one minute you're alright and the next minute you're not.... it's very unpredictable ... if you have an accident and something happens to you and you're in a wheelchair then that's it, you're in a wheelchair and you've got to get on with your life.

What John implies here is that this unpredictability of having MS prevents him from 'getting on' with his life. He cannot adjust to any new impairment, because the nature of his disease means that what he may or may not be able to do varies over time. He goes on to explain how that impacts on his life:

I need something to do; I can't just fester in my house. If I'm feeling OK I want to sort of get involved with [things] but I can't do so much, because it's tiring and it's whatever and stuff like that, quality of life and everything, everything else comes into it ... I've worked all my life, I'm [still young].

The fatigue resulting from MS and the fact that at any moment he may have a relapse, prevent him from engaging into any kind of professional activity. Fatigue means that he only has a certain potential of energy to spend and if he chooses to spend it on a work related activity, he will not have any left to enjoy his life. His comment about his young age may also reflect a common perception that associates illness, impairment and the lack of paid work with old age. Another participant echoed this difficulty in engaging in remunerated activity: "I've tried to go back to work and it just didn't work... it took everything out of me" (Grace). For John, like for others who have spent most of their adult life in work, 'doing nothing' is not a valued option. What really prevents him from re-joining the society of workers to which he used to belong is however not so much the unpredictability of MS itself, as the fact that fatigue and potential relapses make him an unreliable person.

John's point about the unpredictability of MS is echoed in the following comment, by a member of the multidisciplinary team: "The big issue is the uncertainty, you know when is the next episode, what is the next thing that is going to happen...?" (Safiya). When asked how she felt about her relapses, Lucy echoed these words, adding her wish to return to normality after each acute episode: "When you are back in work and feeling all right you just want to get on with it and forget about it all ...

you have just got to carry on, try and be as normal as you can.” For Lucy, relapses are episodes of illness, which take her out of her ordinary life and that she wants to forget as fast as possible. She echoes the economic discourse used by some participants in service A, in which a socially accepted ‘normal’ life is one that engages with remunerated activity. However normality, from the point of view of a person with MS, might encompass the unpredictability of life. A comment by a member of the multidisciplinary team suggests that that may be the case for some people:

Some people I think sort of ... ‘Oh it's another relapse’, and it's almost part of the course but other people it's devastating, absolutely devastating to have a relapse, it's almost like being diagnosed all over again (Safiya).

While some people have integrated the unpredictability of MS as a fact of life, others take each relapse as a personal tragedy. Yet the existence of the relapse clinic itself, in treating relapses so efficiently, emphasises the temporal and curable nature of relapses. Impairments are treated and cured, so that people can go back to their life with functional bodies. The body is only temporarily impaired and the relapse clinic in its efficiency, reinforces this temporality and the uncertainty of timing and extent of the relapses. There is, however, an element of predictability in MS, in that people know they are likely to experience further relapses. With experience, they also acquire a bodily, lived knowledge of what these may feel like. The feeling of uncertainty described here reflects a wider societal concern for predictability. Indeed, a significant part of the tertiary sector of Western economies is built on the unpredictability of life (Reith 2004). Insurance companies, for example, play on an ingrained desire for predictability and entice people to prepare themselves financially for any future eventuality. Similarly, by for example eating healthily, exercising and practicing yoga to invest in some bodily potential, people attempt to buy healthy and happy futures.

I've always kept myself fit ... done half marathons and all that ... but then when you get this ... I'm physically fit and all that stuff you know but you don't realise ... what goes on with your brain, you know what I mean that controls everything, every part of your body (John).

This comment illustrates the societal assumption that a fit body, a body that looks young and healthy, is a body that is not likely to fall ill. It is the illusion of perfect health and eternal wellness that the modern world has generated. In this world, where individual responsibility is paramount, people have to take responsibility for

their own health. John has a very strong body, which he has modelled through years of strenuous training. Yet he now feels prisoner of it, as *it* seems to decide for him what he can and cannot do. With this domineering, controlling body, he has to face a society that can be just as controlling over people's lives and health, albeit often in more subversive ways. John talks about the way in which he has always looked after his body, but finds that it is his brain, an organ associated with the willpower and determination he was proud of, which now controls his movements independently from his wishes. The physicality of his nervous system is becoming a reality from which he can no longer escape. His organ-ised body has taken on a physicality which territorialises him as an intermittently impaired body.

John lives in a society where people have either got to be well and active, or obviously impaired and potentially inactive. MS leaves him in limbo, in a place where he neither feels completely well, nor does he look, or indeed feel, completely able to do things. The unpredictability he faces goes against the principles of efficiency, reliability and predictability on which Western societies are built. People save money and take up various insurances to gain some control over their future, and gain a sense of knowing what will happen. John is confronted with another paradox, which is related to the previous one: that of sometimes wanting to be seen as impaired and other times to hide his condition.

I basically started using a stick and people stay away from you then because they realise you've got something wrong with you... To make it more visible ... but then sometimes you don't want people to realise you've got MS ... you've got a life .... you want to hide it as well so it's like ... you want people to like recognise you in a sense that you've got a disability in a way but then you don't want to show it ...

John needs to be seen to 'have a problem' to get the consideration and assistance he needs in public, but at the same time, he wants to be seen as somebody who 'has a life'. His comments reflect common assumptions in a society where individualisation and physical independence are celebrated values and where one is not to be seen to 'need' assistance.

you can't fight it ... if you're going through it, it doesn't matter how strong you are or anything like that ... whatever is happening to you inside your body, if your body is not going to let you do it, there's nothing you can do about it because ... you've just basically got to wait until you come out of it (John).



John finds himself trapped in a bodily physicality that was unknown to him previously. With it, he has to face the fact that he has no control over the timing and the nature of what happens to his body. He becomes territorialised by his MS-ised body and finds this new territory at odds with other areas of his life. This happens to him in a culture where control, predictability and reliability are regarded as core values, which leaves him in limbo, between needing to be seen as an impaired body, and wanting to hide it. The healthist, medical, economical and individualist discourses are pervasive in his words, reflecting the culture in which he has grown to believe in the good, healthy looking and independent body. What really impacts on his and other people's life, however, is not so much their condition as it is the fact that the unpredictability of their condition is not accounted for in the society they live in.

**f. The relapse clinic and uncertainty**

When asked whether she thought the relapse clinic could have an impact on people's life as a whole, the following professional distinguished between patients recently diagnosed, who may be more aware of the existence of support services, and those who have been diagnosed for longer.

They're still fairly angry that because at the end of the day it doesn't matter that we're seeing them on Thursday, they've still got MS and ... no amount of services and support is going to take that away and they're the people that you sort of worry much more about because I feel more concerned for like their quality of life (Safiya).

According to this view, having MS means having a bad quality of life and since services cannot cure MS, they cannot improve patients' quality of life. In Safiya's view, people who have been diagnosed for a long time think that way. By contrast, people who have been diagnosed more recently are said to engage more fully with support services and therefore draw a real benefit from them. This view comes in contrast with adjustment theories, which propose that the longer people have lived with a disease, the more adjusted they are to it and the better they feel in their life as a whole. Maybe then, what Safiya expresses is that people who have lived for longer with MS have found other sources than the support offered by the service to make their life better. A letter sent by one of the study participants (Paul) long after it had

finished seems to confirm that. It is called 'my positivity' and relates how he has found, through MS, another way of leading a fulfilling life, based on his gift to others. Paul has been diagnosed in the past decade, which Safiya would classify as a recent diagnosis. This highlights a tendency by health professionals to categorise and label people, in a way that may not always account for personal circumstances. Professionals live in and by a striated world, which helps them to produce explanatory categories.

Following Safiya's reasoning, people who have had MS for shorter periods of time may rely more on 'expert' services to support them in facing their condition. This is in accordance with the NSF for Long-Term Conditions (DoH 2005), in which services have to be involved as early as possible in the disease process, so that experience can be guided through professional standards. However, this comes in contrast with patients' views, as most of them said that the relapse clinic did not impact on their quality of life and this was independent from the length of time since their diagnosis. Those who did describe an effect of the clinic on their life as a whole related it to the peace of mind it was bringing to them, to know that they would not have to face their next relapse on their own. They related not to the curing of symptoms, but to the caring attitude of professionals: "for a start it [the relapse clinic] makes you feel that people care... you are not just shoved to one side and... there are people that understand and who are willing to help you." (Paul)

Some professionals tended to see the patients' experience in using the clinic as probably having an impact on their quality of life: "By and large, the patient experience is enhanced and I think that has to be a bonus as far as quality of life is concerned" (Quentin). The difference between professionals and patients regarding their quality of life seems to be related to time. While patients view their relapses within the complexity and longitudinality of their life, professionals see them as discrete acute events. Professionals seem to believe that the way people feel when they come to the relapse clinic is akin to the way they feel about their quality of life as a whole. They also see patients as consumers of health services who face a more efficient system of care and, therefore, must be happier.

A relapse is defined as: “(verb) to become ill again, after apparent recovery / (noun) the return of ill health after an apparent or partial recovery” (Collins English Dictionary 2003). This sets the scene for the ‘relapse’ clinic: the relapse is a deviation from the norm that needs to be treated and brought back to normal. Yet a medical definition of MS describes relapses as part of a condition that is long-term, in that it cannot be cured. The word ‘relapse’ is therefore a denial of that chronicity. In the relapse clinic, MS is indeed treated as a series of incidents or deviations from a norm, albeit individual, in the functioning of a body, which is therefore in need of repair. Patients, who follow that line of thinking and get back to their previous life as soon as possible after a relapse, fit into that model and are seen to benefit greatly from the clinic setting. The defragmentation of the system of care makes it more efficient and comprehensive in a bodily sense and generates this image of the episodic MS within people, which can now be controlled more efficiently. The relapse clinic then, with its aim of bringing people ‘back to normal’, denies them the possibility of embracing MS in its chronicity, with all its peaks and troughs, and of becoming other within the boundaries of their changing physicality.

The uncertainty of the timing, possibility and effect of having a relapse causes bad quality of life and the knowledge that no matter how uncertain, the situation will be dealt with promptly and comprehensively makes for a better quality of life. This is the assumption on which the development of the relapse clinic is based. It offers some certainty in people’s lives. Yet one participant countered this argument by saying:

I've been able to work it out when things are going to happen, you see. I mean, by and large, it's every six months... because I've been quite meticulous, I've been writing it down and when I first spoke to the neurologist I think, and she sort of like pooh poohed ... And it came two days late which was just, which was just as well because they couldn't fit me in at the time that would be like the dead on time... I don't think anyone believed me but that's what happened (Paul).

With experience, Paul has been able to predict with astonishing accuracy when his relapses are going to occur. Yet in this, he does not fit the professionals’ description of the essence of the relapsing-remitting type of MS as being uncertain. Professionals think in a positivistic framework, where things, events and indeed people, have to be defined, categorised and classified. The relapse clinic is used as ‘an ideal forum’ to further study and define with increasing accuracy what a relapse

is. There is a need to produce irrefutable truths in which patients can be framed and which can assist in the curative process. Those who may not fit in these categorisations are “pooh poohed” (Paul), or one worries about their quality of life. In an MS world filled with uncertainty, the clinic brings the certainty of categories and definitions. The professional view makes life with MS seem uncertain, by treating it with certainty. Yet the world is an uncertain place to live in, where no one can really live with any degree of certainty. In the Derridean tradition of hierarchically situated oppositional terms, certainty is seen as the dominant, positive term that only exists in opposition to uncertainty. Certainty is what health services thrive to offer, uncertainty is what people live with. Yet some patients have acquired a lived knowledge of their condition, which enables them to predict with accuracy when their next relapse is likely to occur. What the relapse clinic offers is a conceptually and temporally restricted viewpoint, in that it does not offer people the possibility to embrace uncertainty. This is a reflection of the wider society in which it operates, and in which its users live. Relapses in MS can be seen as an embodiment of the uncertainty of life. People take life insurance policies and carefully plan their future in a society that encourages them to do so. Unexpected events are only accounted for in as much as their likely effect is minimised financially. They are not seen as integral parts of an ‘unregulatable’ essence of life, but as discrete deviations that have to be dealt with.

The defragmentation of care operated by the relapse clinic sits in a Western culture of time efficiency, where time happens in a linear process in which future happenings are the direct result of present actions. The system offers a mastery over future (mis)happenings, in ensuring that presence and support will be available quickly. While this process was seen as extremely positive by the patient - consumer of care, it also introduces a temporal fragmentation of people’s life that denies the long-term character of MS. The relapse clinic reflects a technological and medical ethos, where every service is based on randomised controlled trials that pronounce truths into which patients have to fit. It introduces a striation of people’s lives into ‘diagnostic’, ‘relapse’ and ‘non-relapse’ phases that have to be managed in distinct ways.

## **The end of a journey**

I hope that the reader has found this journey engaging in its dis-order as well as in its content. Rather unlike Deleuze and Guattari's *Mille Plateaux* (1980), in which chapters can be read independently and in any order, this journey was organised to a degree. This is both because I doubt in my ability to reach the level of abstraction of these philosophers, and because reading them requires a level of reflexivity which would not be relevant for a document submitted for examination. So while this section was inspired by Deleuze and Guattari's texts in its rhizomatic structure, it represents the operationalisation of the dilemmas one faces in writing a postmodern thesis, as exposed earlier.

In true Deleuzean and Guattarian tradition, this thesis might not only have been more disorganised, but it could also stop here. This would be so that the reader assumes authorship of her own quality of life conceptualisation, after the textual voyage. However, the production of a doctorate entails an explicit contribution to knowledge. The next section will start by bringing some of the ideas explored together and build on them, in a theorisation that vows to respect the concepts of the BwO and nomadism.

## Quality of life (de)territorialisations

This final section aims, rather ambitiously, to bring together and build on all the strands of thought developed so far. This work has used a framework of long-term conditions to study quality of life, not to reduce it to a health paradigm, but to broaden the health paradigm to include quality of life. In its emphasis on difference, deconstruction and time/space, this approach is at odds with the existing quality of life literature, both in health related studies and in social indicators research. This is not to say that it lacks salience or relevance. My thesis looks at quality of life as it is anchored in the body through long-term conditions, from an anti essentialist perspective. The body's organ-isation through biomedical science is exposed, and its influence is balanced by the possibilities of the BwO. So the medical discourse is not simply rejected as over reductionist, but highlighted as a discursive practice among others.

Writing this final section, I considered presenting it in a nomadic and rhizomatic style of multiple or nodular endings. As explained earlier, I have (dis)organised the textual voyage in a rhizomatic spirit: no chapter comes first in time or importance to the others. Like the chapters in Deleuze and Guattari's *Capitalisme et Schizophrénie*, they can all be read independently from one another. Yet, there is a conceptual thread linking them. Hopefully, they have engaged the reader in looking at life as it appears in the flow of becoming - a patient, a body with and without organs - rather than judging it from a fixed subject position. Philosophy, art, the media, medicine and sociology of the body need not be seen as distinct movements that each examine or represent life in different ways. Each work of art, each research project, each television programme included in my thesis is an expression of life itself, open to many possible interpretations. To combine them in one document is to consider life as a process of constant and multiple becomings. A discussion that clearly states my contribution to knowledge and recommends future directions would clearly undermine this rhizomatic structure by fixing it in a web of academic knowledges. The discussion in a conventional thesis is indeed hierarchically the most important chapter, because it states 'the' thesis. So I was tempted to present

this last section as an additional nodule to my (rhizomatic) structure, and as a mean to further de-structure the document. The following is a brief example of how I might have achieved this.

Like Pinocchio quality of life may sit  
Between life and death  
Health and illness  
Empowerment and disempowerment  
Independence and dependence  
Certainty and uncertainty  
It sits between policy and practice  
Theory and practice  
And other sources of power / knowledge  
Maybe quality of life is about this in-betweeness  
It is neither this nor that  
It is both this and that  
For different people  
In different temporal and spatial spaces  
It is about a deterritorialising potential  
That starts by an awareness of different discursive practices  
In need of deconstructing  
Maybe then, the opposition between constructing  
And deconstructing  
Needs to be deconstructed too  
Just like liberation and striation  
Quality of life is an old quandary  
Looked at here with new lenses  
But what is new and what is old  
What is real and hyperreal  
This thesis has reached its aim if it has sown the seeds of uncertainty  
Of a constant deferral of meaning  
And of the necessity of certainty only in as much as it is temporarily  
And spatially contingent  
Knowledge is historical and provisional  
So quality of life as you know it now should not be

As you will know it tomorrow  
Then again, what is the difference between now and tomorrow  
Between knowledge and ignorance  
...

However, such an ending would only highlight the constant deferral of meaning, rather than offering any kind of explanatory framework – all be it explicitly temporally, spatially and conceptually limited. Reaching the end of this document, the reterritorialisation of quality of life, after the rhizomatic journey, feels like an inescapable ending. I hope it will, however, respect the spirit of nomadology.

The first part of this section offers a reminiscent overview of the textual journey, on which the rest of the section is built. This consists in an exploration of how life with a long-term condition is codified in time and space through health service provision. From this, I attempt to fix what, after all, quality of life may be in a postmodern framework and the ontological, epistemological and practical implications of this. The section concludes by methodological considerations and opens up the possibility of future deterritorialisations.

### **The photo album**

Rather like the traveller coming back home and looking through his photographs, the reader will find in the following paragraphs a short reminder of each of the chapters he found through the textual journey. I make more explicit the intertextual links that I saw as salient, recognising however that the reader may have seen many more, since intertextuality never ends.

As one of the classic Disney features that permeate our popular unconsciousness, *Pinocchio* has much to tell us about our assumptions on the central place of health and the health services in our lives. Disney's version of *Pinocchio* reflects not only the historical moment of its making and broadcasting in Europe, but carries over values of Manichaeism and positivism that remain true today. The postmodern body



is constantly in search of perfection, just like Disney's Pinocchio's quest is to reach boyhood. Yet boyhood was not an end in itself for Collodi and the paths that led to it were numerous and tortuous. Disney, reflecting values of the Enlightenment, tells us that there is only one true, right path, that shown by the experts. One can only speculate on how the two Pinocchios would describe their quality of life: one has grown in wisdom and empathy; the other has largely remained childish and dependable upon trustworthy authorities. One has learned to walk "without strings" (Zipes 1997: 76), or rather has developed a critical mind that enables him to become aware of and choose his strings; the other has gained the strings of compliance, which guide him along the narrow path between right and wrong, health and disease. There is a Pinocchio in all of us and the ways in which we perceive our quality of life may well depend on the strings that form our selves. Pinocchio's strings are the boundaries within which we exist. Rather like Foucault's (1973, 1977) subject that is inscribed by the forces of the social, Disney's Pinocchio is largely made to fit into his role of being the rightful and obedient son of Gepetto. Collodi's Pinocchio fits better in Deleuze and Guattari's (1980) framework, in that rather than, like Disney's puppet, looking for a body, he develops a BwO as he is confronted with the world and grows in maturity. Pinocchio is an animated puppet and as such is both full of life and made to move as if alive. He represents the uncertainty between life and death as, if he looks alive, he is made of wood and aims to reach humanity in flesh.

Using the term quality of life assumes a clear delineation between life and death. Yet the temporal limits of life, at both ends of the spectrum, are disputed medically and ethically. Biotechnological advances, such as stem cell research, also question the sequentiality of the two concepts since older bodies contain within them the potential for further life (Cooper 2006). In other cases, such as in the late stages of terminal illnesses or in advanced dementia, social death may happen before the physical death of the body (Young et al. 1999). In other cultures, life is contained in social groups rather than being the sole property of an individual, and death is a passage to another life (Kirmayer 1988). 'Quality of life' assumes that while life can be quantitatively and qualitatively appreciated, death cannot. The 'quality' of quality of life is what has mostly been disputed ethically, since lives deemed of low quality have been eliminated or sought to be terminated, both in history and in our current headlines. In these cases, the 'quality' of the life in question becomes the rationale

for its end. Life and death are related by the qualitative element assigned to the first. This assignment is linked to the ontological, epistemological and methodical territories explored in the background section of this thesis. So life and death may not be as oppositionally situated as often assumed, but may be related, in particular, by the qualitative property of the first: if someone may be considered to be full of life, one is unlikely to be considered full of death, but the poor quality of the first may lead to the second.

Service development A was designed to provide access to physiotherapy for people who live in a geographically isolated area. There, the analysis shows how one study participant, Peter, has chosen the strings attached to him and operated a deterritorialisation from his patient position, to present himself as a coherent whole, with a body over which he has very little control. The chronicity of his condition and the length of time he has spent in contact with the health services has enabled him to self realise, alongside his body. Other participants' quotes illustrated the necessity of studying quality of life in society as a whole and illustrated how we may value certain social practices more than others. *Pinocchio* presents an example of this, since for Disney the only right path is the one leading to school, even when the bodily reality of the live puppet could have made an extraordinary actor of him. The question is therefore not whether the participants whose bodies are minimally impaired have a better or worse quality of life, but what the conditions are of them conceiving of the concept as measure of worth.

The analysis of service A was also largely based on the assumptions underlying the service, which were linked to the time and place of the therapeutic activity. Time is an important aspect of health service provision in the timing of treatment, as a relation to treatment location, but also on the macro level, in the planning and funding of services. There is a discrepancy between the everyday-ness of a disease like MS and the episodic model of care, and the longterm-ness of the disease and the short term business plans for the services deemed to support them. The NSF for Long-Term Conditions is largely based on the development of a care plan, from the identification of symptoms to death. Whilst this may seem to introduce a model of care based on long-term planning at the level of the individual, it also introduces a greater control over people's experiences. The body is scrutinised both internally

and in the physical and social spaces it occupies. The funding of services developed under the NSF will be in part allocated through the formation of “neuroscience networks” (p63). The focus of these, in allocating funding, will be on cost effectiveness and clinical outcomes, as well as on integrated and multidisciplinary work. This encourages a “systematic audit and evaluation of clinical practice” (p63). Whilst the document talks about the training needs of different professional groups, no mention is made of the time frame of funding streams for individual small-scale services, such as those studied here. Under the NSF, local authorities are expected to demonstrate progress over the three years following the publication of the report, with a view for complete implementation in ten years. Since this evaluation started, the budget for two of the services evaluated, A - physiotherapy in a rural setting - and B - the ACTIVE programme - have been discontinued. Whilst it may be that the individual professionals leading these service developments will gain further funding for similar initiatives in the future, this is far from certain. Until the evidence deemed tangible is produced to show the effectiveness of such programmes, this is unlikely. Scientific evidence is favoured, in a document underpinned by scientific and medical paradigmatic considerations.

The concept of a ‘health service’, represented in this thesis by the NSF and by the three service developments, is based on the notions of health and disease as distinct and opposed categories. Kimsma and Van Leeuwen (2005) show that the medical discourse, which greatly defines our understanding of health and illness, shares its structure with religion, law and economics. The four discursive practices focus on a deviance - disease, sin, crime and scarcity respectively - which is restored through set paths (Kimsma and Van Leeuwen 2005). Culturally, health is equated with beauty, order and life quality (Lawton 2003). The healthy body is organ-ised and functions at an optimum level, which materialises in an aesthetically pleasing body. In this, inside bodily spaces are betrayed, portrayed and are ascertained on the outside. Diseased bodies are dys-organ-ised and belong to necessarily unhappy people. The emphasis in public health is on the prevention of diseases and as such, health is colonised by the prospect of disease (Lupton 2001). Yet healthy people are only healthy by comparison to an other, diseased self and the concept of health is likely to be the subject of multiple re-definitions, as new diseases and cures are discovered.

So the two concepts are not as contrasting as often assumed, as they often co-exist within a body and are ontologically inter-dependent.

Postmodern utopia has shifted perceptions about the body and health in a way that is likely to have a significant impact on the ways in which people conceive of a 'good life'. Morris (2000) asserts that good health is no longer a metaphor for a higher social state and that what matters in the postmodern era, is to *look* healthy. Long-term conditions live in the shadows of the glamorous, healthy bodies on the front cover of glossy magazines. A condition is said to be long-term because it cannot be cured. This chronicity does not sit comfortably in a culture where we increasingly subject our bodies to plastic surgery, in a bid to look younger, thinner, better, healthier. It does not sit comfortably in a culture of quick fixes, radical remedies, and in an image-saturated and fast-lived media environment.

The contemporary television programmes included in this study, by largely under-representing long-term conditions, reinforce the cultural assumptions highlighted in *Pinocchio*. While the Disney feature highlighted an ingrained search for bodily perfection, much of the television programming, at least in July 2005, was based on the restitution narrative, as introduced by Frank (1996). In this paradigm, health is the norm that contributes to a good quality of life, whereas disease is a deviation from that norm, which in itself is enough to produce a bad quality of life. This is at odds with some of the qualitative literature describing long-term conditions as overall sources of positive experiences (Paterson et al. 1999; Lutz and Bowers 2005). Yet this is also the overwhelming assumption in the NSF for Long-Term Conditions, which depicts an inherent rejection of the diseased 'other' as different from a normative healthy self. The restitution narrative fits acute, episodic models of disease, which are at odds with the longitudinality and the incurable character of long-term conditions. Within the limitations of this analysis in mind, it appears that the popular media seem to favour a paradigm that denies a life of quality to people who have to live within unpredictable and often limited bodily possibilities. It does so by framing people with long-term conditions as such and in opposition to illusory stable and predictable bodily possibilities.

People who are framed as diseased come to *depend* on professionals and carers. The term is three dimensional, as it can refer to an addictive characteristic, to a reliance on others, or to something that is undecided or pending. Independence, as non-dependence, signifies an organ-ised body that decisively functions optimally, without professionals, carers or harmful substances. Yet the dichotomy between dependence and independence seems simplistic, as we are all inter-dependent beings. Technologies are created to make impaired bodies more independent, in that they require less manpowered support, but these bodies become entirely technologically reliant. So the dependence recommended by national policy documentation such as the NSF is one that is less costly, rather than less dependent than the previous state. The ACTIVE programme also fits in this dualism, as it was designed to maintain independence through exercise. In order to counter this Manichean dependence / independence duality, Gibson (2006) introduces the notion of connectivity, as a signpost for extended and fluid subjectivities, which embrace changing abilities with time.

Prior to the development of the ACTIVE programme, participants' MSised bodies were made to rest in confined and restricted spaces over an uncertain and indefinite time period after diagnosis. In contrast, in the ACTIVE programme, the body is required to move in specific and regulated ways and it becomes self-monitoring. Hence, the body is malleable and can be conceived of as the outcome of health care practices and discourses, as they define and regulate it in time and space (Frank 1991; Turner 1992). The health care system, which exists and is based on the medical paradigm and uses its discourses, can be considered as an institution of normative coercion (Turner 1992), in that it disciplines individuals and exercises forms of surveillance over daily life (see for example Wheatley 2005). Yet, it is not always coercive in an oppressive manner, as most participants to the ACTIVE programme accepted its authority as legitimate and took part in it voluntarily. A paradox emerges, in that this programme, while based on disciplinary practice, came for many participants as a counter for previous bodily inertia initiated through medical advice. In the non-existence of a cure and the limited effect of dietary and lifestyle guidelines, surveillance was limited to six-monthly appointments with a consultant neurologist. Beyond this, the condition was mostly treated as a series of acute relapses, managed by steroid treatment. Participants described feeling 'out on

a limb' and 'useless' without any form of regular and on-going monitoring. Over time and space, bodies were left to their own devices, as the disease progressed. Individuals were de-possessed of their own body, as they were told that there was nothing they could do, but rest and wait. The uncertainty of the progression of the disease was used as a threat, in that people were repeatedly told that they may 'make things worse'. Patients were encouraged to listen to medical advice and were told to stop listening to their own body – a point demonstrated eloquently by Jane, on page 145 -, as the damage caused by MS could only be assessed through formally validated scales of functional status or MRI scans. The ACTIVE programme empowered participants to increase their control over their body, through the exercise sessions.

Empowerment and disempowerment are not dialectically and hierarchically situated, but rather reflect the possibilities of subjectification as exposed by Frank (1998). In being subjectified, a person has the potential to exert agency and to be subjected to technologies of power. Deleuze and Guattari's framework of the BwO describes a similar concept, in that if one is disempowered within a particular territorialisation, one also holds the possibility of agency, deterritorialisation and liberation. Calls in policy documentation to empower patients both suppose and reinforce a pre-existing power imbalance. In television programmes, people are subjectified to eat healthily, exercise or live in tidy homes. In the ACTIVE programme, participants become the agents of their rehabilitative possibilities. Conceptually, from the moment that a body is with organs, it is divorced from its own power source and therefore disempowered, as intensities of life are made organic. Not only is power a more fluid entity than the concept of empowerment may lead us to assume, but political power carries its own contradictions in requiring us to negate our sense of responsibility, by fixing it in time and space. The NSF for Long-Term Conditions provided an example of this.

Barilan (2005) asserts that the story of the body and the story of the person are kept separate in the contemporary medical ethos. "The anatomical body is read as a book of nature written solely by the biological and physiological dimensions of human life" (Barilan 2005: 198). The NSF, in being primarily concerned with the body and its dys-functions is a prime example of this. Over the past few decades, it has

become commonplace that medical practice should consider its patients holistically, using Engel's (1977) bio-psycho-social model, for example. However, a closer examination of the NSF, in highlighting a curative and evidence-based ethos (p1; 15), reveals a 'bio-heavy' version of this. Barilan (2005) notes that

The high culture of the affluent West does not treat the person through his or her body, but only according to his or her mental competence. The other side of this Cartesian-like disembodiment is the depersonalisation of the body (2005: 210).

In the NSF, bodies are required to function to certain standards in order to enable the person to be 'independent' and improve his quality of life. The care plan opposes the inherent uncertainty of living with a long-term condition with the certainty borne out of the organisation of diagnostic and treatment phases. Inherent in the care plan is an assumption of life with a long-term condition as difficult because of this uncertainty, which is contrasted and therefore reinforced by the rigidity of the care plan. Indeed, the organisation of a series of diagnostic tests at the onset of symptoms, for example, introduces the certainty of dates, appointments, technology and results. This appears in contrast to the uncertainty of symptoms and therefore reinforces it by virtue of its oppositional dualism.

The level of uncertainty of life with a long-term condition is linked with the perceived risk of developing complications, having relapses or flare ups. So the way in which we conceive of risk is crucial to our sense of certainty and stability in life. Adams (2005) shows the relativity of risk and how people may be much more tolerant of a greater risk if they believe in its ineluctability. Reith (2004) analyses risk as the reification of a probability. On one hand, this feeds in to the scientific paradigm and on the other, this reification represents a rejection of uncertainty. Risk is calculated to be avoided and produce greater certainty over one's future. For example, the public health discourse uses probabilistic categories to encourage people to adopt preventative health measures (Lawton 2002). Health becomes pathologised in this process, in as much as current signs and symptoms, such as high BMI for example, become the precursors and predictors of future illnesses. In other words, the more uncertainty is ascertained, the more people use this as a rationale to gain greater control - certainty - over future happenings. So uncertainty, or the knowledge of it, produces certainty. On the other hand, an outcome is only certain on the basis of the same probabilistic terms that measured uncertainty. Contracts,

such as the care plan recommended by the NSF, frame the experience of living with a long-term condition in terms of avoidance of future bodily happenings. The uncertainty of the future functional status of a body is given as a negative, and countered by the organisation of care patterns.

The relapse clinic offers a pertinent example of the model of care advocated in the NSF. It is responsive, supportive, efficient and user-friendly, and opposes a fixed structure to the uncertainty of the timing and extent of impairments caused by a relapse. It operates a paradigmatic shift, in that within the relapse clinic, people are considered as bodies rather than symptoms or body parts, which live in connection with a person who has a life outside of MS. However, the untold story of the clinic is that of the people who do not fit in its strict admission criteria. People's lives are fragmented, in time and experience, in a bid to oppose certainty and organisation to the inherent uncertainty attributed to MS. This process denies the chronicity of the condition and treats it as a series of acute episodes, from which people will be brought back in a speedy and efficient manner. Inherent in the service is the opposition between the desirability of health where life is certain, predictable and of good quality, and the undesirability of disease, which brings uncertainty, unreliability and poor quality of life.

### **The codification of time and space in disease management**

Quality of life may be less about the formal, conceptual reasonings and technical procedures developed by health care workers, politicians, philosophers and academicians, than about an unreflective, corporeal and private way of being that is intuitively attuned to the passing moment. The time and space in which quality of life is considered is therefore critical to a better understanding of its conceptualisations and representations. This is explored in the following paragraphs.

The time and space of everyday life has been described as interplay between codified and normalised practices of 'official' and institutional practices, and 'unofficial', experiential and chaotic practices (Burkitt 2004). The ACTIVE programme (service



B) and the relapse clinic (service C) are evident exemplars of such codifications, in time as well as in space. The ACTIVE programme is designed for people of certain bodily abilities, regardless of the time spent since diagnosis, and happens in the shared time-space of the group sessions. The relapse clinic treats patients at a precise and non-negotiable time in their illness trajectory, in a shared space and time where disciplinary knowledges are exerted. While this may not appear as straightforward in the rural physiotherapy service (A), it too had a function in the normalisation and codification of the human experience. While most institutional practices take place in a defined geographical space, such as the hospital, the physiotherapist in A, Tim, delivers his care during home visits. These allow him the time to give instructions and remind people of what they ought to be doing. In doing so, these introduce regimes of care into the patient's house, as a building. Power, then, is exerted in an engaging, rather than repressive, way. The hospital, where consultants work and exert their knowledge on diseased bodies, is more easily identified as being repressive (Foucault 1973). The relapse clinic showed that this is not always the case though, as people came out of it feeling that they had been listened to in a more emphatic manner than ever before. However, the health care professional who, like Tim, comes to the home, knows the body so that he does not have to rely on people's experiential accounts of it, and has developed a relationship with the family, may offer a more seductive model of care.

The use of technology to promote independence in the NSF corresponds to another codification of personal home space. In the relapse clinic, time is fragmented through a defragmentation of the system of care. In the ACTIVE programme, where time is shared, participants dispute the timeliness of the sessions in relation to the time of diagnosis. The informal activities that people perform in their daily lives are more dispersed across time and space than these official, codified practices. Family relationships have developed over time and grown with the disease. For some of the participants, the MS-ised body has become a physical site for the happenings of their everyday lives.

Study participants, in for example wanting to go on short-term vacation in service A, offer a resistance to the medical discourse. They demonstrate that the MS-ised body, as the object of health care practice, is not the unique locus of the self and does not

live in isolation of one's immediate social environment. Rose (1992) asserts that the current view of the self

resonates with basic presuppositions ... that are embodied ... in our ideal conceptions of what people should be... The guidance of selves is no longer dependent upon the authority of religion or traditional morality; it has been allocated to 'experts of subjectivity' who transfigure existential questions about the purpose of life and the meaning of suffering into technical questions about the most effective ways of managing malfunctions and improving quality of life (1992: 141-142).

While the 'experts of the body', health professionals, see the core of their mission as addressing technical challenges to correct malpractices and improve quality of life, they also and increasingly take the psychological and lived dimensions of living with a long-term condition on board. This psychologically and technically driven agenda is both lead by and echoed in national health policy documentation (DoH 2005).

The realms of people's life take place in a personal, mindful space, in which some have created for themselves an alternative to the health services' codification and normalisation, which can be qualified as a rejection of, and resistance to, the medical discourse. Some participants have chosen to base their sense-of-self on the separateness between their body and mind and, in doing so, abide by the assumptions of the dominant biomedical discourse. They engage equally with the texts of the health services, in acknowledging and accepting their inability to cure MS and with that of their own subjectivity. This ability to forge these intertextual links enables people to see their physical condition with fatalism and to situate the quality of their life in what they remain in control of. In this, some of the participants challenge the assumptions on which the health service developments were based. Their subjectification has happened over time, as an instrument of self-realisation.

This subjectification of the body with organs leads me to consider what quality of life may represent for the bodies with and without organs and to re-place my thesis in the web of Deleuze and Guattari's concepts.

## Quality of life, philosophically

The BwO is a biological and political experimentation (Deleuze and Guattari 1980), where pleasure is sought, not as a reference to notions of lack or emptiness, but rather as a state where desire is a positive state in itself and does not *lack*. So the renunciation of a desire for cure, if developed as and by a BwO, represents a conquered state, where desire is not defined by the sufferance of a lack of cure, but by the fullness of the act of desiring. Pleasures and hopes, even the most superficial ones, are territorialisations, Deleuze and Guattari (1980) assert. A BwO is best made where there are only intensities, where there is neither me nor the other, not in favour of a superior intensity, but in a celebration of singularities that could not be more individual. So desire, seen as a positive resource that does not imply lack through the BwO, is what could constitute a good quality of life.

Quality of life measurements assume an essential reality to quality of life, in which individuals evolve and position themselves. There is a 'good' or 'bad' quality of life, measured through the conditions of one's environment (objective), or the way one places oneself on this absolute (subjective). I suggest that the opposite is true. Quality of life is not an absolute, but more a support to deterritorialisation. Quality of life deterritorialises itself when, for example, it becomes irrelevant to Peter in rural area A. The subject is not an absolute, since she fabricates her self in dialectical relationship between her unconscious and her environment. Therefore a person and her quality of life are not two distinct 'things' that can be apprehended or measured, but territorialisations in language. The quality of life that is aligned with lack and desire is a smooth space occupied by the self. Like the nomad, the self can *be* the space, and occupy it in deterritorialisations. Deleuze and Guattari (1980) assert that "the nomad is the Derritorialised by excellence" (1980: 473) because in his case the deterritorialisation does not occur after something or from one place to another. Rather, it is deterritorialisation that constitutes his rapport with the earth. In a similar way, a nomadic spirit would not simply operate deterritorialisations from somewhere to somewhere else, but would rather see this process as a way of life. His quality of life would then be a line of flight - series of deterritorialisations - immeasurable, impossible to appreciate. The nomadic spirit would not so much move between territorialisations, as be deterritorialisation in a space, life, that it occupies.

Therefore the nomadic spirit does not make life any more than it makes him. The nomad adds to life in small ways, which may change direction and intensity with every territorialisation. Life as the space of the nomadic spirit comprises elements in the timescape, such as a diagnosis for example, which occur in a rhizomatic fashion. These events vary in space and intensity in the timescape of life. Within this rhizomatic structure, the nomadic spirit occupies space without possessing or transforming it. At the same time, it is that space. If events become nodules in a rhizomatic space, they cease to be differentiable or measurable, and therefore one can no longer describe how 'good' or 'bad' something is, because it simply is. This is not to deny their distinctiveness, rather the opposite. Events become unique because they are lived, instead of being codified and standardised through measurement.

The BwO is constructed bit by bit, place by place and condition by condition, without ever being reduced to any of them. It continuously evolves conceptually in time and in space. The challenge to obtain a BwO as a smooth plateau is to bring all the deterritorialisations together, in a way that can no longer be affected by external factors. At the same time, we can never complete our BwO, because there is always a new territorialisation after an old one. So we can never assume perfect liberation, and as there are always new stifling territorialisations to be challenged, we can only aspire to true nomadism. Happiness can itself be a territorialisation, as from the moment it becomes measured, it is stratified and as restraining as our body with organs. Happiness, rather than quality of life, can become a line of flight as defined by Deleuze and Guattari, but only if it remains an intensity, a sensation, rather than a measured quantity. It is not, as psychologists might assert, a positive affect (Sirgy 2002), but rather a deterritorialising potential. This would start not by a deterritorialisation of happiness as a positive attribute and non-happiness as a negative one, but rather a perception of them without judging, attributing or qualifying. Happiness then becomes experimentation on this plan of sensations and desires. It is not a signifier, as that presumes a striating interpretation. It may be signified, but no sign will do justice to its intangibility.

I talk about happiness, rather than quality of life, as being a deterritorialising potential. This is because the term of quality of life, as exposed through this work, is

steeped in modernist ideology and based on illusory dualisms such as those deconstructed here. But happiness has to do with quality of life, in as much as if it is this intangible sensory dimension of a BwO, then this would translate in a contentment that could be captured by many quality of life measures.

Deleuze and Guattari (1980) state: “signification sticks to the mind not less than the organism to the body” (1980:198), and it is not easy to see beyond it. To separate consciousness as a measured, examined quantity, from the subject, is neither easier nor more difficult to do, than to separate the body from its organs. To escape subjectivisation is to tread a fine line, between productive liberation and destructive madness. One has to keep enough of the organ-ised body so that it can re-form and live. One has to keep some significations and interpretations, even if it is to then face them with their inconsistencies. One does not fabricate a BwO by blind de-stratification and dis-organisation. Violent rejection of stratification leads to death and destruction. This is not what the BwO is about. Striations are only bad when they impose themselves as unavoidable truths and negate other possibilities. The point of having a BwO is therefore to recognise any theorisation, signification, interpretation as a striation in need of questioning.

### **Quality of life, ontologically**

Gardiner (2004) describes the everyday as a way of relating to the world that is characterised by an elusory quality, which resists the technologies of power by remaining largely unnoticed. He asserts: “the everyday remains an inchoate and heterodox mix of fluid, multiple and symbolically-dense practices and ways of feeling and knowing” (2004: 230) that resist assimilation. Quality of life has much to do with the everyday defined in such a way. The everyday is the invisible backdrop to our quality of life, it impacts on how we perceive and define it. As exposed at the beginning of this thesis, although it has been the subject of considerable academic debate, quality of life escapes succinct and consensual definitions. Derrida has introduced the notions of writing, intertextuality, undecidability, deconstruction, *différance*, trace and supplement. These concepts all

stress the instability of meaning and its deferral through the interplay of texts (Cilliers 2005). Accordingly, categories and words do not have essential universal meanings and do not refer to objects that possess essential qualities, but are social constructions of language. They are territorialisations. Quality of life is therefore not a fixed universal 'thing', but a description in language. It is only through the identification and deconstruction of the underpinnings of this description that we can approach an understanding of how we conceive of quality of life in certain contexts and circumstances. The textual journey undertaken by the reader has hopefully highlighted the intertextual qualities and undecidability of quality of life. What this work has aimed to do, rather than conceptualise what quality of life *is*, is to identify the concepts associated with it in contemporary discourses and in relation to long-term conditions and the health services, and to deconstruct them. This is done in a bid to disrupt, rather than fix, the meanings attributed to quality of life: this work represents an effort to deterritorialise quality of life through a deconstruction of its underpinning constructs. However, every deterritorialisation ends up on a reterritorialisation. So does this thesis.

Discourses do not free quality of life, they invent it, make it into a problem to be measured, monitored, improved. A good quality of life is said to happen in a bodily state that is described as healthy, independent, empowered and which evolves in a world of certainty. This is because the biomedical model is the dominant discourse in our cultural understanding of life with a long-term condition. It frames our understanding of health, illness and everything that happens to us once we are pronounced ill. A poor quality of life necessarily results from the diagnosis of a long-term condition, because it almost certainly leads us through states of dependence and disempowerment. In this thesis then, the deconstruction of quality of life necessarily leads to a deconstruction of the dominance of the medical model and some of its major assumptions.

Quality of life is territorialised as a concept through medical, health, economic and moral discourses. The extent to which people, who are territorialised as patients, engage with this quality of life territory influences the way in which they think about their life. Their BwO grants them the possibility to engage to different degrees with this territorialisation, and this impacts on the way in which they feel about their life.

So quality of life is territorialised and becomes a text in itself, where powerful discourses enter in intertextuality, and people who have been diagnosed are territorialised within that territory.

What, then, might quality of life *be*? Well first, it does not exist beyond discourse, and in the context of the dichotomy between health and illness, it is mostly territorialised by the biomedical discourse. In the context of the health services, it is territorialised in terms of a less costly independence and an empowerment that reinforces the initial power / knowledge imbalance. In the context of a scientifically minded ethos, it is territorialised as poor when uncertainty is inherent. Quality of life is necessarily individually based, in that people determine their amount of engagement with the predominant quality of life territorialisations, through the possibilities of a BwO. In traditionalist terms, it is therefore necessarily subjective, but not only, since the BwO engages in a dialectical relationship between the *unconscious* and the environment. Quality of life therefore also necessarily relates to an objectively measurable environment, but not only, since the conditions of existence of this environment are discursively produced.

### **Epistemological territories**

The extent of an individual's engagement with different quality of life territorialisations is necessarily temporally and spatially contingent. This may lead the reader to think that quality of life may be related to the difference between an individual's life circumstances and his or her adaptation to them. This is reminiscent of Calman's definition of quality of life: "A good quality of life can be said to be present when the hopes of an individual are matched and fulfilled by experience" (1984: 124-125). So health services may raise people's expectations so that these no longer match reality. People like Ron or Stuart in rural area A know that there is currently no cure for MS, but cannot help hoping that one will be found sometime in the future. As time goes on, Ron's hopes have become nearer to the reality of what can, or cannot, be done about his MS. So over time, it is not the conditions of his life that have improved, but rather his expectations that have come nearer to the reality of

his life. However, such a conceptualisation assumes a coherent and linear progression in one's life circumstances and between this, and one's potential revisions of life possibilities. Quality of life is related to an individual's capacity to engage in deterritorialisation from the premise of limited bodily possibilities, in order to create a more fitted territory, in which he can feel happier. But deterritorialisation is only ever temporary. To assume a linear and coherent direction to one's deterritorialisations in life is to start their striation as a process of adaptation that can be assessed, measured, encouraged and therefore controlled.

Related to Calman's definition, but more empirically tested and theoretically sophisticated, is Cummins' (2003) theory of subjective well-being. According to Cummins, subjective well being is a hard wired system, homeostatically controlled to keep us within a set range of well being. This system works exactly like that regulating our blood pressure or blood sugar levels and, like these, the wellbeing homeostasis is prone to failures, which may lead to depression. In Cummins' model, these homeostatic disruptions are pathologies in need of psychological treatment. His theory is therefore psychologically based and physiologically inspired, and only acknowledges the influence of the environment (cultural, political) in as much as it challenges the homeostatic balance. It does, however, grant human beings with adaptation possibilities that may be assumed as similar to a deterritorialising potential. His, however, is a positivist theory, which, based on extensive quantitative data, poses itself as an all-encompassing explanatory narrative. There is therefore a crucial philosophical difference between his perception of well-being and my account of happiness as desire which needs to be untamed and hence unmeasured to be realised. Other points of divergence are the fact that his work on *subjective* well being assumes a dual and oppositional relationship at odds with this thesis. Although Cummins' theory is appealing in terms of the possibilities it supposes and its strong theoretical basis, it still appears reductionist from a postmodern viewpoint. That is not to say that it is better or worse than my propositions, but simply that it posits itself as truth with strong explanatory powers. The underpinnings of happiness proposed here, by contrast, contain within them the necessity for constant movement, change, deconstruction and deterritorialisation. It takes as a given the impermanence of meaning and Derrida's principle of meaning as endlessly deferred (Collins and Mayblin 1996).



Quality of life, as conceptualised in the medical model, obscures, and to a degree, inhibits, the possibilities of the BwO. In other words, the medical discourse's conceptualisation of bodies with failing or malfunctioning organs silences the possibilities of the BwO. The same goes with Cummins' (2003) homeostatic system. The scientific discourse from which it emerges is dominant in our popular and general culture and we therefore live in a striated environment that is not conducive to deterritorialisation. That is not to say that it does not happen, we have seen examples in this thesis when it clearly had, but simply that it is not a recognised process and that these voices tend to be silenced (or understood as delusory) by a dominant discourse in which they do not fit. This may be because by nature, deterritorialisation cannot be striated as each new territorialisation of the BwO requires a new departure. It results from this that quality of life cannot be measured, but can simply be experienced, in an acknowledgement that this experience is only a passing moment.

### **Quality of life as a deterritorialising potential: practical implications**

Concrete implications for health care practice can however be drawn. The first is an acknowledgement of the dominance of the biomedical model not only in health care professionals' understanding, but also in the political direction given to the health services and in our culture as a whole. The second is a need to recognise that while the medical model makes continuously tremendous discoveries to help the body with organs, it silences the possibilities of the body without them. This is not to say that we should negate or reject the medical model, but simply that we should hear other silent voices, such as those emerging from the BwO. Fox (1993) introduces the concept of 'arché health' to contribute to such an agenda:

Arché health is the *becoming* of the organism which made it possible for the first time to speak of health or illness... It can never become the object of scientific investigation, without falling back into discourse on health/illness. It is not the outcome of deconstruction of these discourses, it *is* deconstruction or intertextuality, difference and becoming... every BwO has an arché-health, which is its becoming. Whereas health and illness territorialise the BwO with their discourses, arché-health is the force of desire, or resistance (1993: 140, emphases in the original text).

Maybe then, with such lines of flight, could we help ourselves - and this does not apply only to people with long-term conditions - to embrace our inevitably changing life circumstances. This could happen in recognition that cures may be discovered one day, but that in their absence life need not be left in limbo, with the trace of an unimpaired body. People with long-term conditions live with and without impairments. Their bodily possibilities change over time and space, in a culture where certainty and reliability are paramount. Yet the reality of their body, and ours, as one that contains within it the possibility of long-term disease, could exist in a smoother space, where the body is not at the core of life. Deterritorialisation could become a recognised, rather than covert and intimate, practice. Of course this would lead to a striation of deterritorialisation, in need of conceptual and practical deconstruction. This would need to be acknowledged. So maybe the one practical step that could be taken to help deterritorialising processes would be to deny prominence to scientific and medical discourses. Not to reject them, but leave place for alternative and more liberating discourses for some people, some times, in some spaces.

Quality of life, as it is currently conceptualised and exposed in the background section, extends the possibilities of the medical model, but does not challenge its dominance. Quality of life as conceptualised by social indicators researchers is wider and more global. It seeks to inform governments on the state of happiness of its subjects and as such, has a wider focus than quality of life as conceptualised within health studies. However, they too create encompassing explanatory categories that do not leave space to alternative view points. Social indicators researchers lead the development of quality of life as a recognised academic discipline. As such, their approach is broader than those adopted in the health care paradigm, since it includes economic, educational and social dimensions to humanness for example. However, this academisation sits within a scientific positivist paradigm, which can be just as disempowering as medicine. Within this framework, quality of life does not question existing paradigms, but merely occasionally extends them. Quality of life researchers face a dilemma, in wanting to develop an alternative, quality of life centred, paradigm and needing to use accepted discourses to be heard and recognised. In this, although it is more ambitious and broader, their challenge is similar to mine in writing this thesis.

## **Quality of life practice**

The conceptualisation of quality of life as a potential for deterritorialisation has implications beyond health care practice. These relate to what I now term quality of life practice, by which I mean the measurement of quality of life and its potential for education, for society at large and for disability studies.

### **a. Measurement**

If quality of life should be conceptualised as an evolving process of deterritorialisation, should we attempt to measure it? And if yes, how could we do it? Health care providers want outcomes that they can act upon. In other words, the health care paradigm wants to engage with quality of life in as much as it enables it to fit into politically supported consumerist discourses of patient choice and empowerment, but this does not lead to a questioning of its assumptions. This is an example of what Deleuze and Guattari (1980) would have defined as a science that reproduces different schemes from the same view point. Quality of life is only a new data form to be collected in health care practice. However, reproducing science is inevitable and necessary, so long as it represents a temporal and spatial territorialisation only. Some regret the use of the term 'health related quality of life', arguing that it is not so much quality of life, as it is a measure of health status in disguise (Michalos 2004). In as much as it measures quality of life according to strict and predetermined criteria that place health and the functioning body with organs at the core of personhood, health related quality of life is not related to feelings of contentment or happiness as conceptualised here. However, if using the concept means that some professionals within the health care system are starting to engage with the body with organ as a whole and as an entity within physical and social spaces, like in the relapse clinic, then it has to be a positive step.

I said earlier that quality of life should remain unmeasured, as measurement is a striation that denies the liberating potential of the concept. It remains that we live on an apparatus of concepts that, in a capitalist postmodern world, need to be measured to exist. So while I personally believe that quality of life should be a desire, a sensation, a line of flight developed by and through a body without organs, while I

see concepts as territorialisations of the soul, I am resigned to acknowledge the need for constant reterritorialisations. The BwO engages in a dialectical relationship between the unconscious and its environment and, in the hands of free spirits, concepts oscillate between territorialisations. So while I consider measurement unfortunate, I realise that my thesis would deny the world it emerges from by proscribing it.

Prutkin and Feinstein (2002), in their “pathogenesis of quality of life measurements”, argue that quality of life is a state of mind, not a state of health and that the best way to assess it may be to simply ask people how they feel. This puts primacy in the subjective sense of self and reflects the objective / subjective dichotomy already disputed. However, in the sense that their conceptualisation puts the person and her desires at the centre of the evaluation, rather than placing her on a scale of concepts, it makes conceptual sense. In a similar vein, the SEIQoL (O’Boyle 1993) asks people what is important in their life, regardless of their bodily, financial or social possibilities. While many people have attempted to derive from it what generally is important in people’s life and use it to inform the development of other tools, the SEIQoL in itself is less prescriptive. It offers a more focused approach than Prutkin and Feinstein’s, in that it focuses on five chosen life areas. The fact that it ranks them by order of importance and satisfaction to derive an overall score is, I think, less pertinent, although it does have the advantage to permit communication with a wide paradigmatic audience.

#### **b. Potential for education**

If we are to help people territorialised as patients to deterritorialise themselves and to develop their BwO, maybe the first step would be to challenge the formal education of health care professionals. This would entail their early exposition to an array of paradigmatic positions, rather than a late introduction in relation to research at postgraduate level. This is not to say that an education centred on the organ-isation of the body is inadequate. Rather the opposite: it is crucial, but would be enhanced rather than undermined by early exposition to alternative views. As with the other dualities explored in this thesis, I argue more here in favour of a both / and, rather

than an either / or view of the world. Practically, these insights might include alternative therapies, caring or long-term conditions in a generic sense and as part of an enriching paradigm, or a focus on discursive practices, for example. It would entail a greater influence of medical sociology in general, and postmodernism-influenced sociological accounts of the body, health and illness in particular, on curriculum development. In order that deterritorialisations may become a more recognised way of living rather than coping with long-term disease, patients themselves should be actively involved in curriculum development and delivery.

**c. Potential for society**

A recognition of the possibilities of deterritorialisation has wide implications for society at large, not only for how we conceptualise quality of life of people with long-term conditions, but also of all the people who are perceived as vulnerable in one way or another. Rose (2001) describes how society as a whole has taken on the administration of our well-being:

A whole range of pressure groups, campaigning organisations, self-help groups have come to occupy the space of desires, anxieties, disappointments and ailments between the will to health and the experience of its absence (2001: 6).

This is compounded by what Clarke et al. (2006) refer to as the biomedicalisation of postmodern societies, in which high technologies such as CAT scans are made available to consumers for early pathological detections. They state:

The biomedical governmentality to “know thyself” that is associated with such bodily techniques often relies on a neo-liberal consumer discourse that promotes being “proactive” and “taking charge” of one’s health (2006: 181).

This biomedicalisation movement contributes to the fabrication of biomedicalised subjectivities that impact on social structures (Clarke et al. 2006). This assumes a customisation of medical techniques that have overtones of consumer empowerment, but which is merely a new technologically-enhanced territorialisation of our selves. It derives from this that an emphasis on deterritorialisation should not focus solely on how we come to think about health and disease, but also such concepts as independence, empowerment and risk in biotechnologically-advanced societies. These concepts are being redefined by technological advances and new territories are

being created from which we should be able to deterritorialise our selves. This is not to say that these territories are good, or bad, but merely that they exist and present an evolution from the modernist medicalisation of life previously experienced. Many of us are just starting to become aware of the existence and potential impact of new biotechnological advancements on our life. It is a territorialisation in the making, which will affect us differently in time and space, and which we may want to engage with in the recognition that a new deterritorialisation will soon be required. It emerges from this that embracing a nomadic way of apprehending life should help us recognise emerging territories and negotiate our way through them, in ways that can best contribute to make us happy.

### **Quality of life and disability studies**

This thesis sits both with-in and with-out disability studies. By taking both a broader and a narrower focus (see page 40), it blurs the boundaries of disability studies. Maybe it is that while a disabled identity indisputably exists, this is not the case for long-term conditions, which by their status of 'conditions', sit in a medical paradigm. The defining chronicity relates to the temporal aspect of life with a diagnosis. 'Condition' relates to the dys-organ-isation of the diagnosed body. So long-term conditions relate to the body which, with its disorganised internal spaces, sits in a timeframe that is seen as fluctuating, uncertain and therefore difficult to control.

Long-term conditions are both defined by a medical paradigmatic position and appear to challenge it through their chronicity. However the answers provided by the NSF for Long-Term Conditions (DoH 2005) for example, follow the rules of a science that reproduces. Long-term conditions therefore merely extend the medical discourse rather than representing a real challenge, as the answer provided is a reproduction from the systems put in place to deal with acute states. There is no such thing as a 'long-term condition' identity, even though there may be, for example, 'MS', 'cancer' or 'diabetes' identities. I am not sure whether I advocate the creation of one, politically active movement in the image of the disability movement, or if an extension and strengthening of existing movements would be more effective. In

either case, and whether people see themselves as physically impaired or disabled by their environment, it remains that the only public territories for people with long-term conditions to adopt are those of the 'able' and 'dis-abled' identities. The in-betweenness of their state may not facilitate a deterritorialisation from 'able' to 'not-quite-disabled', 'potentially disabled' or 'temporarily disabled' identities. This duality between ability and disable-ness (disability / impairment) leaves people with long-term conditions between the conceptualisations of the medical discourse and those of the disability movement, neither accounting for the whole of their selves. What would be more productive is a fundamental challenge to the assumed able / disable duality, to encompass all bodies as able only temporarily and spatially.

### **Methodological considerations and future deterritorialisations**

The final content and structure of this thesis is the result of many debates between my supervisory team and myself. It results from the inherent tensions between the demands of a postmodern stance and the requirements of an academic thesis. As a result of this, as much as through the theoretical framework underpinning it, this work is temporally and spatially contingent. Most research endeavours aim to undo understandings in order to propose new ones or extend the old ones. That said, they often 'add to knowledge', but rarely question the knowledge or power that pre-existed them. This revealing of silent voices, in the case of this thesis that of the BwO, is a strength of postmodernism, but also one that may make it difficult to engage with. A thesis, when it claims allegiance to postmodernism, I feel should not only question reasonable assumptions rather than merely add to them, but also question the conventional structure of what a thesis is expected to adopt. This is my rationale for the dis-organisation used. Deleuze and Guattari (1980) state:

In a book like in any other thing, there are articulating and fractioning lines, there are stratifications, territories; but also lines of flight, movements of deterritorialisation and destratification (1980: 9-10).

As such, a book can be a stratifying edifice, but can concomitantly contain deterritorialisations that can open up possibilities for a BwO. So while I hope this thesis creates knowledge in a way that will be academically recognised, I also hope

that it will extend - ever so gently - the frame of reference within which theses are formed and examined.

I have exposed throughout this work my understanding and use of the concepts of nomadism as conceptualised by Deleuze and Guattari (1980). Fox proposes that, methodologically, reflexivity / intertextuality and action research fit in a nomadic framework. Through this work, I wish to propose an alternative view, which entails a nomadic textual approach. However, methodology, being prescriptive about the right way to enquire and produce knowledge, is seen as stifling in a postmodern framework. In Deleuze and Guattari's conceptualisation, it would be considered as an epistemological striation of the world. What I hope this thesis has demonstrated, is that postmodern need not be obscure and accessible only to a select few. I have proposed here a *physical* nomadism, in between texts, that incorporates the playfulness of words and sources, as an acknowledgement of the complexity of quality of life as a concept. The (rhizomatic) structure of the textual journey, I propose, is therefore a structural operationalisation of nomadism. I use parentheses, because as a PhD thesis this work cannot have a true rhizomatic structure: it has a beginning, an end and organising lines of thoughts in it. But Deleuze and Guattari's (1980) concept of a rhizome inspired me in the un-structuring of the textual journey.

I have approached quality of life both through different texts, and as a text itself in need of deconstruction. This flexibility is inherent to my understanding of nomadism. It is not presented here as the right way of 'doing' nomadism, but rather as one possible approach, which inherently recognises its own limitations. This is because:

The fact that our knowledge is limited is not a disaster, it is a condition for knowledge. Limits enable knowledge. Without limits, we would have to incorporate life, the universe and everything into every knowledge claim we make. Limiting frameworks makes it possible to have knowledge (in finite time and space). At the same time, having limits means something is excluded, and we cannot predict the effects of that exclusion. Knowledge is a fragile and, above all, contingent thing (Cilliers 2005: 263-264).

This thesis therefore does not claim the status of truth, but rather values a constant process of questioning. It is limited by the particular texts it includes as well as by my particular interpretation of nomadism. However, because of these, it would be



difficult to reproduce and does not itself reproduce anything, therefore, fitting into the characteristics of a science that follows.

What follows are therefore not suggestions on how my approach could be used elsewhere, but rather further deterritorialisations that I would wish to follow in the future. The reader will hopefully have formed many others. This could take the form of an exploration of the ways in which health care professionals could encourage or facilitate deterritorialisation in practice. The way in which individual practitioners would translate this into a practice that is accepting of the other, the non compliant or difficult patient for example, would depend on how they themselves would engage in deterritorialisation. A study of professionals who have themselves experienced care as patients with long-term conditions would shed some light on people's potential for deterritorialisation. From then, explorations could be done with them as to how to raise awareness of the discursive and territorialising forces that shape people and set seeds to break boundaries between them. An extension of this, which would place such a study in our biotechnologically advancing society and focus on the implications of this on the formation of our selves, would be another possibility.

A second possibility would be an exploration of the ways in which health professionals could be trained in a way that acknowledges the possibilities of the BwO. I exposed earlier how patients could be more involved in curriculum development and delivery. This would help to break boundaries between the knower and the learner. Any such boundary breaking is a deterritorialisation, which eventually will help acceptance of the other. This could also lead to an exploration of the possibilities of the BwO outside of the biomedical model of health and illness. For example, in a capitalist society dominated by economical discourse, could a good quality of life be the possibility of a deterritorialisation of our earning selves?

Quality of life could be explored as a territorialising force in itself. This would highlight the possibilities of the concept, which has tremendous potentialities, both liberating and striating. This duality between liberation and striation would (of course) need to be deconstructed too. This would therefore be an extension from this

thesis from a health related frame to one that defines and constitutes quality of life, through conceptualisations developed by social indicators researchers for example.

These suggestions should be taken as further deterritorialising potentials, all building towards lines of flight along which quality of life could be apprehended, felt, experienced and represented in a nomadic way.

# Epilogue

I still wonder what it would be like if I hadn't been attracted to a nomadic way of life in the first place. I would probably have stuck to critical theory as a conceptual framework for this thesis. I hope that what I have written instead offers more possibilities and that it opens them up in a way that shows that the 'us' - healthy people - and 'them' - diagnosed bodies - are only bodies and selves submitted to a range of territorialisations. Cultivating our deterritorialising potential and occupying the space of life in an un-organised manner should be important to all of us. So unarticulated in this thesis and emanating from these reflections is a deconstruction of one last dichotomy, that between us and them. This should be done in a bid to open up acceptance of the Other as a differently territorialised being who can choose deterritorialisation as a way of life. The 'us' or 'them' dualism is therefore as artificial as the other oppositional pairs deconstructed here.

Fortunately, the postmodern position I adopted prevents me from providing a firm and measurable quality of life definition. The theorisation I offer as part of this discussion should be seen as more of an academic requirement than a forceful ontologisation. Postmodernists concern themselves with 'how' certain positions come to be accepted as truths. Quality of life, as exposed throughout this work, is viewed through the lenses of a post-Enlightenment modernity of belief in the scientific theory of causation and in the ability to ultimately control problems through rational, administrative and possibly coercive, power. Quality of life is fixed in time through the concept of risk, and in bodily spaces (health, illness), social spaces (empowerment, risk) and conceptual spaces (life, death). These concepts often act as signifiers for the text of quality of life and, as such, limit its frame. Quality of life is therefore territorialised to fit regimes of truth that may be as destructive as they vow to liberate. Of course, I, as the author, saw these constructs as key in contemporary conceptualisation of quality of life in long-term conditions, at the time of the making of this thesis. They are deconstructed here because I came to this work with my lived experiences and prejudices, at this time in my life. Anybody else undertaking the same work would have probably chosen different texts and

highlighted different constructs underlying quality of life. If I was to start this work again in five years time, it would undoubtedly look markedly different. This work is a product of the time and space of its making and can only gain relevance through this acknowledgement.

The current renewed concern for quality of life, particularly in relation to health interventions, and particularly in relation to long-term conditions, has in its own making as much potential for liberating and oppressive power. This concern is not inherently 'good' or 'bad', but steeped in socially and politically undermining ideologies. Only by becoming aware of these can we begin to challenge them, become 'other' and assume full responsibility for a construct that is undecidable by nature. What has been critiqued in this work, is not the necessity or benefit of the pursuit of a preventative and curative enterprise. There has been tremendous progress in medicine and health care over the past decades, which have undoubtedly positively affected the lives of many people with long-term conditions. In that sense, striation enables progress. However, striation inhibits progress and denies otherness when it comes to encompass the whole of people's lives and posits itself as undisputable 'truth'. Rather, what is highlighted here is the striation of our lives. It is the ambiguity between the discourses of free independent will and agency and the way in which care plans are being presented as the one and only way forward in which every individual has to fit. Like the Blue Fairy had a very precise idea of what the right path was, the National Service Framework is the path drawn by our current government for people with long-term conditions. In this postmodern society, we are all made into Disney's Pinocchios, in stark contrast to the unruly and vibrant but more responsible puppet created by Collodi. Collodi's puppet grows and becomes other in a way that is denied to us by documents such as the NSF.

One is seen to have a good quality of life in long-term condition when one remains independent, empowered, healthy, has the certainty of one's future and ignores the possibility of death. These cultural and political assumptions form an often unrecognised, but taken for granted, definition for quality of life, which is very reminiscent of that posited by the Perfectionists. It presents itself as universal truth and therefore forms the kind of meta-narrative objected to by postmodernists. Part of the contemporary appeal for quality of life undoubtedly lies in its adoption of a

language of empowerment and liberation. As such, it mirrors the individualistic discourses used in health education, appeals to notions of self control and creates similar conditions of subjectification. Like the body-without-organs, quality of life may be conceptualised individually, in a dialectical relationship between a self, a body and a cultural and social environment. As such, individually, it can only be a fluid entity that evolves in time and space, evades definition and remains undecidable. Measuring quality of life is fixing it, conceptually as well as in time and space, and therefore denying it this fluidity. At the same time, a forceful rejection of any measurement possibilities will not engage the striated world in which we live and, therefore, runs the risk of feeding the status quo, rather than challenging its boundaries.

I hope that, reaching the end of this work, I have succeeded in my aim to disrupt the meanings ascribed to quality of life in our society. This work aims to create the space for a conceptualisation that is based on individual circumstances and that acknowledges the assumptions and prejudices of the society in which we live. By recognising and disrupting these discursive practices, my hope for this work is to extend the boundaries within which we perceive and conceive quality of life. Striation is only good if it leads to a continuous process of deterritorialisation and re-territorialisation that disrupts meanings to enable other meanings to emerge. This temporal disruption will have led to necessary but hopefully short-lived re-territorialisations as I write, and the reader reads, these words. As highlighted many times during this work, any newly formed conceptualisations - whatever they may be - are themselves territorialisations in need of deconstruction. In the act of writing these words, I have begun to striate the smooth space created during the (rhizomatic) textual voyage. Any deterritorialisation results in a reterritorialisation that needs to be challenged. This may start as soon as I put a final full stop to this thesis.

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